

School of Pharmacy

Help-Seeking Behaviour of Men in Regards to Lower Bowel Symptoms

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**This thesis is presented for the Degree of
Doctor of Philosophy
of
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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Human Ethics The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007)—updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number # **PH-02-12** and from Sir Charles Gairdner Hospital (Approval Number # **2012-153**)

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Abstract

Background: Lower bowel symptoms such as rectal bleeding, change in bowel habit and abdominal pain are common. However, persistent symptoms, especially among those in middle and older age groups (≥ 40 years), and in those with a history of benign bowel conditions such as ulcerative colitis or Crohn's disease, have been linked with an increased risk of colorectal cancer. Studies conducted in the past two decades have suggested that one in three individuals may experience rectal bleeding at some point in life, however; many of them do not seek timely medical advice. The literature review conducted as part of this thesis found that most people attributed their lower bowel symptoms to chronic bowel conditions such as haemorrhoids or delayed seeking medical advice about their symptoms for a number of factors including psychosocial and demographic. The review also provided evidence there was limited information on men's help-seeking behaviour.

Aim: The current thesis aimed to understand and explore the help-seeking behaviour of men with regards to lower bowel symptoms along the trajectory of illness.

Objectives: The four objectives of the thesis were to explore the help-seeking behaviour of men:

- i. Regardless of whether they had ever experienced lower bowel symptoms
- ii. Experiencing symptoms but not seeking medical advice
- iii. Diagnosed with benign colorectal conditions
- iv. Diagnosed with colorectal cancer.

Methods: The objectives of the thesis were met through four separate studies (studies 1-4) conducted as part of this thesis respectively.

Study 1 was a survey of a representative sample of men in the general population (in Western Australia), whether or not they had ever experienced bowel symptoms. The objective of Study 1 was to determine what advice the participants would give to other men experiencing lower bowel symptoms. Participants were asked to review a series of web-based clinical vignettes involving men (portrayed by actors) with lower bowel symptoms. Clinical symptoms (rectal bleeding, diarrhoea, and unexplained weight loss) used in the vignettes were selected based on their prevalence in the population and the risk of colorectal cancer (CRC), as well as chronic bowel diseases associated with these symptoms. The other

variables used in the development of the vignettes were the age of the person in the vignette (younger or older men) and the duration of symptoms (lasting for three days or three weeks). A total of 28 vignettes were developed. Eight vignettes were randomly selected from this set of 28 for each participant. The random selection of vignettes was facilitated by an algorithm embedded in the web-based software used for the survey. Participants were then asked whether the person in the vignette should seek medical advice and, if yes, where and how urgently they should seek advice. Responses were used to determine the factors (clinical, demographic and psychosocial) that could impact on the advice that participants would offer to other men about seeking medical advice for lower bowel symptoms. The Health Belief Model was used as a theoretical framework for this study. An expert group comprising five general practitioners (GPs) also answered the vignettes. The participants' responses were then matched with the responses of the expert group to explore the factors that would predict whether the participants would agree with the expert panel.

Studies 2, 3 and 4 used qualitative methods to explore the barriers and facilitators to help seeking in men who had first-hand experience of lower bowel symptoms, at different stages of their help-seeking trajectory (i.e., men who had never sought medical advice for their symptoms (Study 2), men diagnosed with chronic or benign conditions (Study 3) and men with CRC (Study 4). Participants for Study 2 (n=13) were recruited from the general population. For Study 3 (n=19) and 4 (n=20) participants were recruited from a hospital setting. These three studies used semi-structured open-ended interviews to explore the help-seeking behaviours of participants and the sample selection methods were exclusive and non-random. Andersen's Model of Total Patient Delay was used as the theoretical framework for all three qualitative studies. Andersen's Model describes five major stages of delay: appraisal, illness, behavioural, scheduling and treatment. The details about Andersen's Model have been provided in Section 4.3.1.

Results

Study 1 (cross-sectional survey)

Sample: Four hundred and eight participants (response rate 51%) reviewed eight vignettes each. A total of 3264 observations (408x8) relating to 28 vignettes were collected in the data. Seventy-six percent of the sample was aged between 30 and 59 years, 18% of the sample was aged ≥ 60 years and the remaining between 18 and 29 years. In regards to education, 28% of the sample was university educated, 50.7% up to Year 12, and 20% was qualified in technical/trade occupation. Sixty-seven percent were employed full-time and 14% were retired or pensioners. The proportion of sample earning \leq \$50,000 (AUD) was 64%, and

those earning between \$51,000-100,000 (AUD) was 23%. Approximately 74% of the participants were married or were in a *de facto* relationship. Fifty-one percent of the sample visited their GPs ≤ 1 per year.

Results: Respondents aged ≥ 50 years had nearly two times higher odds to agree with the expert panel in regards to advising the men in the vignettes to seek advice from a GP compared with those aged < 50 years (OR: 1.88, $p < 0.01$). Respondents who lived in regional or remote areas (OR: 0.43, $p < 0.01$), and those who had studied up to Year 10, (OR: 0.43, $p < 0.01$) had lower odds of agreeing with the expert panel. Participants with higher incomes were also more likely to agree with the expert panel. Participants who visited their GP at least once per month had 16 times higher odds to agree than those who never visited their GP (OR: 15.9 $p < 0.01$), and those who believed that visiting a GP was time-consuming were 60% less likely to agree (OR: 0.4 $p < 0.01$). In regards to clinical symptoms, participants were more likely to agree with the expert panel regarding rectal bleeding (OR: 1.0 (reference group) than diarrhoea (OR: 0.26, $p < 0.01$) or weight loss (OR: 0.14, $p < 0.01$), and when multiple symptoms occurred concurrently (OR: 4.37 $p < 0.01$). Seventy three percent (1517/2076) of the respondents had recommended seeking advice from a GP. Others recommended seeking advice from other health professionals such as community pharmacists about their lower bowel symptoms.

Studies 2–4 (qualitative studies)

The results were presented as barriers and facilitators to help seeking based on the themes generated from participant interviews

Barriers to help seeking

The themes that emerged from Study 2 (n=13) regarding not seeking medical advice for the symptoms were the rationalisations of symptoms such as haemorrhoids (n=4/13), self-management of symptoms through over the counter (OTC) drugs and advice from community pharmacists (n=4/13) or changes in diet (n=5/13) and attributing the symptoms to on-going mental and physical stress (n=3/13) and to haemorrhoids, fear of cancer diagnosis (n=2/13) and the time involved in consulting a GP (n=6/13). In Study 3 (n=19) the main themes regarding barriers to help seeking were symptoms not warranting medical advice (n=17/19), absence of pain as a symptom (n=4/19), diet (n=4/19), stress (n=4/19) and non-persistent symptoms (n=5/19). Lastly in Study 4 (n=20), the main themes identified as barrier to help seeking were attribution of symptoms to common illness such as haemorrhoids (n=11/20), diet and/or alcohol (n=4/20), symptoms not warranting medical advice (n=6/20), intermittent symptoms (n=4/20), and fear of cancer diagnosis (n=4/20).

Further, lack of time to arrange an appointment with a GP was reported as a barrier by participants across studies 2 (n=6/13) and 3 (n=5/19).

Participants diagnosed with both benign or chronic conditions (Study 3) and malignant colorectal pathology (Study 4) made assumptions about the cause of their symptoms, such as inappropriate diet, excessive alcohol or coffee, lifting heavy weights at work, medical conditions or side effects of medications. Men in these two subgroups also cited fear of unpleasant investigations and cancer as barriers to seeking advice at an earlier stage. The embarrassment associated with disclosing lower bowel symptoms was a common theme that emerged as a barrier to seeking help across the three studies (studies 2–4). However, a family history of cancer acted as a barrier for a few participants diagnosed with cancer and prevented them from visiting a GP in a timely manner in studies 3 and 4. Similar to the findings of Study 2, participants in Studies 3 and 4 bought OTC medications for symptom relief.

Facilitator to help seeking

Encouragement from family or friends (especially a female family member) was a facilitator to seeking help in men diagnosed with both benign/chronic bowel diseases (Study 3; n=7/19) and those with cancer (Study 4; n=7/20). The exacerbation of existing symptoms or the appearance of additional symptoms such as abdominal pain were facilitators to help seeking among men diagnosed with both benign and malignant bowel conditions (Study 3, n=9/19 and Study 4, n=7/20). A family history of bowel cancer was also an encouraging factor in help seeking in Study 4 as one of the two participants with family history of bowel cancer sought timely advice when he experienced the symptoms.

Conclusions: Delays in help seeking are common among men experiencing lower bowel symptoms. Men often ignore their symptoms; however, at times they may visit other healthcare professionals such as the community pharmacists for persistent symptoms prior to seeking advice from a GP. Interventions aimed at facilitating men to seek timely medical advice for their symptoms must aim at increasing access to health services especially to geographically isolated populations and those with lower socio-economic status. Based on the results of the qualitative studies, interventions should also consider the role of family (especially spouses) in encouraging men to seek timely help, and the increased role of community pharmacists in referral of men with symptoms and considered at high risk of cancer to GP.

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2. Oberoi DV, Jiwa M, McManus A, Hodder R. Men's help seeking behaviour with regards to lower bowel symptoms. *American Journal of Health Behaviour*. 2015; 39(2): 182–91. DOI: <http://dx.doi.org/10.5993/AJHB.39.2.4>.
3. Oberoi DV, Jiwa M, McManus A, Hodder R. Men's help seeking behaviour with regards to lower bowel symptoms. *American Journal of Health Behaviour*. 2015; 39(1): 22–33. DOI: <http://dx.doi.org/10.5993/AJHB.39.1.3>.
4. Oberoi DV, Jiwa M, McManus A, Hodder R. Help-seeking experiences of men diagnosed with colorectal cancer: a qualitative study. *European Journal of Cancer Care*. 2014. DOI: 10.1111/ecc.12271.
5. Oberoi DV, Jiwa M, McManus A, Hodder R. Colorectal cancer: applying a gender lens. *Quality in Primary Care*. 2014; 22(2): 71–9.

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1. Oberoi DV, Jiwa M, McManus A, Hodder R. Help seeking behaviour for colorectal cancer (CRC) symptoms: applying a gender lens. *European Journal of Cancer Care*. 2014; 23:4.
2. Oberoi DV, Jiwa M, McManus A, Parsons R. Do men know which lower bowel symptoms warrant medical attention? A web-based video vignette survey of men in Western Australia. *European Journal of Cancer Care*. 2014; 23:4.
3. Oberoi DV, Jiwa M, McManus A, Hodder R. Health-seeking trajectory of men with regards to symptoms of colorectal cancer: a qualitative study. *Asia Pacific Journal of Clinical Oncology*. 2014; 10:177.

Conference Presentations Related to This Thesis

International conferences

1. Oberoi DV, Jiwa M, McManus A, Hughes J. The New Partnerships in Primary Care Cancer Research organised by The Cancer and Primary Care Research International Network Winnipeg, Canada, 10–13 June 2014. (Poster).
2. Oberoi DV, Jiwa M. North American Primary Care Research Group Conference, New York, 21–25 November 2014. (Oral).
3. Oberoi DV, Jiwa M, McManus A, Hodder R. World Cancer Congress, Melbourne, Australia, 3–6 December 2014. (Oral).

National conferences

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Abbreviations

ASR	age-standardised rate
AMTPD	Andersen's Model of Total Patient Delay
BMI	body mass index
CRC	colorectal cancer
DOR	diagnostic odds ratio
GEE	generalised estimating equation
GI	gastrointestinal
GP	general practitioner
HBM	Health Belief Model
HRQoL	health-related quality of life
IBD	inflammatory bowel disease
IBS	irritable bowel syndrome
LR	likelihood ratio
NICE	National Institute for Health and Care Excellence
OTC	over the counter
OR	odds ratio
PPV	positive predictive value
SUDD	symptomatic uncomplicated diverticular disease
UK	United Kingdom
US	United States of America
WA	Western Australia

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Chapter 1: Introduction

1.1 Background

1.1.1 Help-seeking behaviour in regards to lower bowel symptoms

The lifetime prevalence of rectal bleeding in the general population is up to 38% in many Western countries ⁽¹⁻³⁾. Changes in bowel habits, described as a change in the frequency of defecation, consistency of stool and difficulty of evacuation ⁽⁴⁾, is estimated to have a lifetime prevalence of up to 19% ⁽²⁾. The symptoms are often associated with a range of bowel disorders and timely help seeking is central to the early diagnosis of bowel pathology, both benign and malignant. Help-seeking is a problem-focused planned behaviour involving interpersonal interaction with a selected healthcare professional ⁽⁵⁾. The process of help seeking begins with the recognition of symptoms, and leads to the decision whether or not to seek help ⁽⁵⁾. It starts with symptom perception and may be followed by a series of possible actions (such as self-medication, disclosure of information to significant others such as family or friends) or ignoring the symptoms. Seeking medical attention is the last step of the help-seeking pathway ⁽⁶⁾. Andersen's Model of Total Patient Delay (Andersen's Model) proposes various stages at which the delay may occur during the pathway from the onset of symptoms to the appraisal of symptoms and the point at which the person decides to seek help or begins medical treatment ⁽⁷⁾.

In general, most people attribute their lower bowel symptoms—such as rectal bleeding, change in bowel habit and/or unexplained weight loss, which may indicate colorectal cancer (CRC)—to chronic diseases, and do not seek timely medical advice ^(8, 9). The rate of help seeking for rectal bleeding varies between 14% and 45%, and there has not been any major improvement over the past two decades ^(3, 10-12). Thompson et al. ⁽¹⁾ observed that nearly one in three individuals who consulted their GP for rectal bleeding had previously purchased over-the-counter (OTC) preparations. There is limited information on help-seeking behaviours for change in bowel habit; however, a few studies conducted over the past two decades showed that fewer than 10% of people prefer to go to the medical practitioner for diarrhoea. Most people prefer to first visit a community pharmacist, while some people delay or do not seek medical advice at all ^(2, 13, 14). In contrast, symptom such as abdominal pain is often strongly associated with seeking timely medical advice. They have the shortest time frame from symptom onset to help seeking ⁽¹⁵⁻¹⁷⁾.

Factors that may influence the decision to seek help are classified as psychosocial, demographic or behavioural in nature ⁽¹⁹⁾. The main factors that may facilitate help seeking

for symptoms include greater perceived seriousness or severity of the symptoms, persistence of symptoms, pain or discomfort caused by the symptoms, social pressure from relatives, age of patient (>45 years) and emotional response to symptoms^(11, 12, 16, 19-21). Demographic factors such as socio-economic status, marital status, health insurance (public or private) and ethnicity, as well as behavioural factors such as embarrassment associated with symptoms and the belief that the condition will clear up spontaneously, may also influence help-seeking behaviour^(18, 22-24). Studies have reported that people may delay seeking advice if they feel uncomfortable disclosing their symptoms with a GP, if they may be worried about the outcome or if they decide to wait and watch believing that the symptoms would resolve spontaneously, or because of a lack of time to visit a doctor^(2, 11). Some people are reluctant to seek help because of anxiety and avoidance regarding the diagnosis⁽⁷⁾.

Ristvedt and Trinkaus⁽⁸⁾ observed a mean delay of around six months in help seeking for the symptoms of rectal cancer, with 17% of people in their study delaying for up to one year. Pederson et al.⁽²⁵⁾ observed rectal bleeding to be associated with longer patient delays compared with other symptoms, whereas Hamilton and Sharp⁽²⁶⁾ observed the maximum delay in help seeking for change in bowel habit. Atypical or vague symptoms may increase the likelihood of delayed presentation to a GP, as patients may be less concerned about their symptoms^(27, 28). On the other hand, the challenge for GPs in referring patients for a colonoscopy or to a specialist clinic may be that very few patients presenting with symptoms will actually have cancer⁽²⁰⁾. This may limit referrals to only those cases that are suspected of cancer. Although early diagnosis and treatment of CRC may improve the quality of care of patients, it does not affect survival in bowel cancer patients⁽²⁹⁾. It may also improve the chance of successful treatment⁽³⁰⁾. In a systematic review of the factors affecting pre-hospital delays in the diagnosis of CRC, Mitchell et al.⁽¹⁶⁾ found that there was no relationship between age, gender or socio-economic status and help seeking. Among the behavioural factors, non-recognition of symptom seriousness, lack of knowledge either about the disease and symptom denial led to increased delays. Fear of cancer diagnosis or the associated investigations and fear of powerlessness were other factors contributing to patient delay. Additionally, people who self-diagnosed or self-medicated delayed seeking medical advice⁽¹⁶⁾. In a recent study on the help-seeking behaviours of Australian adults with regards to symptoms of CRC, Courtney et al.⁽²⁾ found that people delayed seeking advice because they did not recognise the seriousness of their symptoms, denied their symptoms, were embarrassed about the symptoms or believed that the symptoms would resolve spontaneously.

1.1.2 Risk of pathology in regards to lower bowel symptoms

Lower bowel symptoms may be indicative of a continuum of bowel pathologies, ranging from haemorrhoids (rectal bleeding) to chronic bowel conditions such as symptomatic uncomplicated diverticular disease (SUDD), which has an overall incidence rate of over 30% in individuals aged ≥ 50 years⁽³¹⁾. Diverticular disease may further affect up to 70% of individuals above 80 years of age. Other chronic bowel diseases may include inflammatory bowel disease (IBD), presenting with symptoms such as rectal bleeding, diarrhoea and weight loss and irritable bowel syndrome (IBS), presenting with altered bowel habits, bloating, intermittent abdominal pain or discomfort and mucous in the stool. In some cases these symptoms may be indistinguishable from diverticular disease, which may present with similar symptoms in addition to fever^(31, 32).

Not only are the lower bowel symptoms common in the community, they are also known to affect health-related quality of life (HRQoL) in individuals experiencing these symptoms. Individuals with diverticulosis may experience diminished HRQoL affecting physical, psychological and social health, even in the absence of clinically overt attacks⁽³²⁾. This may lead to work disability affecting an individual's ability to earn a living⁽³³⁾. Resulting unemployment or absenteeism from work and receiving a disability pension are further associated with diminished HRQoL in patients with IBD^(34, 35). These symptoms may also be suggestive of CRC. Lawrenson et al.⁽³⁶⁾ observed that there were 200–400 cases of CRC per 10,000 patient years in individuals experiencing change in bowel habit and rectal bleeding, respectively. Symptoms such as rectal bleeding, changes in bowel habits and abdominal pain are independent predictors of CRC⁽³⁷⁾. Rectal bleeding is a classical and frequent first symptom of CRC, and it may be present in up to 84% of cases, although it may also be prevalent in up to one-third of the general population^(3, 4, 14, 38–40). Change in bowel habit may be present in up to 77% of CRC cases and in nearly 10%–25% of the general population^(14, 38–41).

However, past studies have shown that while rectal bleeding [diagnostic odds ratio (DOR): 2.6, 95% CI 1.9-3.6] and weight loss (diagnostic OR 2.9) may have diagnostic values for CRC, other lower bowel symptoms, such as diarrhoea [DOR: 0.9 (95% CI 0.4-1.7)], constipation [DOR: 1.5 (95% CI 0.8-2.8)], change in bowel habit [DOR 1.5 (95% CI 0.8-2.8)] and abdominal pain [DOR 0.9 (95% CI 0.4-1.70)] have relatively poor diagnostic values^(42, 43). Although lower bowel symptoms are commonly reported in primary care, the risk of cancer in patients with rectal bleeding in the absence of any other lower bowel symptoms is nearly 1 in 700 in the community as reported by Thompson et al.⁽¹⁾. These authors also reported that in most cases rectal bleeding resulted from benign causes and the

risk of CRC increased only with age and where the bleeding was accompanied by peri-anal symptoms such as anal pain, soreness and discomfort, swelling, itching, lumps and prolapse. On the other hand, a higher proportion of participants in their study were referred to the hospital if they experienced additional symptoms such as change in bowel habit and/or dark bleeding; however, majority of those (83-92%) were not diagnosed with cancer, thereby proposing for a reassessment of these symptoms as criteria for referral to hospitals ⁽¹⁾. A GP is not likely to encounter more than one case of CRC per year in primary care and most cases presenting benign bowel conditions ^(14, 20-22). This suggests that up to 97% of patients with rectal bleeding seen in primary care may not have cancer, but they may have diminished HRQoL ⁽²³⁾.

There is limited information on the help-seeking behaviours of Australian men who experience lower bowel symptoms, but do not seek medical advice, hence delaying a diagnosis. This is a cause of concern, particularly because the estimated incidence rate of CRC in Australia is among the highest in the world ⁽⁴⁴⁾. As the rate of help seeking with regards to lower bowel symptoms is lower than desired, it is important to understand the barriers to help seeking for such symptoms. The current study sought to explore and understand the reasons for men's reticence to seek medical advice for their lower bowel symptoms in order to identify the major barriers to help seeking. People experiencing rectal bleeding in the absence of peri-anal symptoms are nearly three times as likely to be at risk for CRC and almost twice as likely to be at risk for chronic bowel pathologies, such as colitis and polyps, than those with peri-anal symptoms ⁽⁴⁵⁾.

The risk of CRC in patients with rectal bleeding may increase further in the presence of other lower bowel symptoms such as change in bowel habit (loose stools or increased frequency of stools), unintentional weight loss and abdominal pain ^(11, 36, 40, 43, 45). Although abdominal pain as a lone symptom is not a strong predictor of CRC (odds ratio [OR]=3.9; 95% confidence interval [CI]=3.6-4.3) compared with other lower bowel symptoms such as rectal bleeding (OR=20; 95% CI=17-23) or change in bowel habit (OR=14; 95% CI=12-17), factors such as male gender and increasing age may further point to its association with cancer ⁽⁴⁶⁻⁴⁸⁾. The increased risk of CRC in males is discussed in detail in Section 1.1.4. The National Institute for Health and Care Excellence (NICE) in the United Kingdom (UK) recommends referring patients with persistent lower bowel symptoms to specialist healthcare services. Urgent referral is recommended for patients aged ≥ 40 years with rectal bleeding and diarrhoea persisting for six weeks or more, and for patients aged ≥ 60 years with rectal bleeding or change in bowel habit persisting for six weeks or more ⁽⁴⁷⁾.

Most people experiencing symptoms such as rectal bleeding, change in bowel habit and abdominal pain are diagnosed with benign bowel pathology (e.g. polyps) or chronic diseases such as haemorrhoids, IBS or IBD^(43, 49, 50), leading to a diminished HRQoL, including work disability^(33, 44, 51, 52). Longstanding benign bowel conditions may progress to CRC in some cases. Eaden et al.⁽⁵³⁾ observed that the risk of CRC in people with IBD increased with the duration of disease and was estimated to be 2% and 18% after 10 years and 30 years of disease, respectively.

1.1.3 Need for this research

The current research seeks to explore the help-seeking pathways of men in Western Australia (WA) in regards to lower bowel symptoms, and to explore the factors that may affect their decision to seek medical advice for their symptoms.

In Australia, around 20%–30% of the population experiences rectal bleeding, and nearly one in three people experience diarrhoea or constipation at some point in their life^(10, 38). It has been estimated that nearly one in five people do not consult a GP for rectal bleeding or for change in bowel habit, and nearly one in three of them delay seeking medical advice for more than three months^(11, 38). In their study on the representative adult population, aged 40 years and above, in the State of New South Wales, the most populous state in Australia, Cockburn et al.⁽¹¹⁾ found that majority of the population was aware of rectal bleeding as a symptom of CRC; however, fewer than 50% knew about other symptoms indicative of CRC. Population and hospital-based studies in different parts of Australia in the past 15 years have found similar rates of help seeking in regards to lower bowel symptoms, as well as similar reasons for delays in seeking or not seeking medical advice. In their community-based sample of adults (n=338) in Penrith, Sydney, Eslick et al.⁽¹⁰⁾ observed around 18% of the sample had noticed blood in stool in the past one year; however, less than one-third of people (31%) who noticed rectal bleeding sought medical advice. The majority of people seeking medical advice were aged 30–60 years. Cockburn et al.⁽¹¹⁾ reported that in their study conducted with a random community-based sample of Australian adults in New South Wales (n= 1332), nearly one-third of the participants had not visited their GP for rectal bleeding. However, among those who sought help, nearly all the participants had visited their GP within three months of symptom onset. Additionally, in their study men were significantly less likely than women to have information about the symptoms of bowel cancer (68.85 vs. 83.3%). In yet another Australian community-based study Courtney et al.⁽³⁸⁾ observed that 18% of people who ever experienced rectal bleeding and 20% of those ever experiencing change in bowel habit had never consulted a doctor. In their hospital-based retrospective study on the delay in diagnosis for CRC (n=100), Young et al.⁽⁵⁴⁾ reported that 34% patients

had a delay in diagnosis of more than three months from the onset of symptoms and 53% (n=18) of these delays were related to delays in seeking medical advice by the participants. Furthermore, male patients in their study were more likely to delay help seeking than females (31% for males vs. 10% for females; $p=0.011$). There have been recommendations to focus on the need to improve people's knowledge about the potential risks associated with persistent lower bowel symptoms and the benefits of timely help seeking through public education programmes; nevertheless, the success of such programmes is varied ^(11, 38). Thus, if the barriers to help seeking are to be addressed, policy makers must have a comprehensive understanding of the factors that facilitate or impede timely help seeking among men.

Worldwide, the annual incidence of CRC is nearly one million and it is the fourth-largest cause of cancer-related deaths, with higher mortality in men than in women (age-standardised rate: 374 vs. 320 per 100,000) ⁽⁵⁴⁾. Australia has the highest age-standardised incidence of CRC in the world, accounting for 12.7% of total cancers and 10% of all cancer deaths Australia wide ⁽⁵⁶⁾. In 2008, the average number of new cases of CRC in Australia was 43.8 per 100,000 individuals ⁽⁵⁶⁾. Projected number of new cases of CRC in Australia was for the Year 2015 is 9500 for males and 7950 for females and for the Year 2020 is 10,800 for males and 9160 for females ⁽⁵⁶⁾. Over the past three decades (1982–2010), the incidence rate of CRC in Australia increased by nearly 11% among men (from 66.5 to 73.7 cases per 100,000 men), but remained fairly stable among women (from 51.9 to 51.1 cases per 100,000 women) ⁽⁵⁷⁾. CRC was estimated to account for up to 13% of the burden of disease due to cancer in Australia, and for 69,400 disability-adjusted life-years lost due to premature death or disability, disease and injury ⁽⁸⁾. In 2010, the lifetime risk of CRC in Australia up to the age of 85 years in the general population was 1 in 10 for men and 1 in 15 for women ⁽⁵⁸⁾.

No relationship has been found to date between the duration of symptoms and the staging of the tumour at diagnosis or the mortality rate associated with CRC ^(59, 60). However, a reduced interval between the onset of symptoms and the diagnosis and treatment resulting from early symptom recognition and reporting may improve the chances of successful treatment with regards to complete tumour removal ⁽³⁰⁾. As the five-year survival rate for CRC is a factor of the stage of cancer at diagnosis (five-year survival rate of 93.2% for Stage 1 vs. 8.1% for Stage 4) ⁽⁶¹⁾, timely help seeking and medical intervention may help lower the associated mortality rate. On the other hand, the success rate of CRC treatment is compromised with delays in seeking help for the associated symptoms ⁽⁶²⁾. It is therefore unfortunate that only 1 in 5 Australians with CRC are diagnosed at Stage A cancer (early stage) while nearly 40%

are diagnosed with late-stage cancer (Stage C and Stage D, as per the Australian Clinico Pathological Staging System [ACPS])⁽⁶³⁾.

Studies have reported that in general, men have lower health literacy than women and are less knowledgeable about specific diseases and risk factors, as well as about health⁽⁶⁴⁾. They also delay seeking medical help after the development of symptoms⁽⁶⁵⁾. In their study on a age and sex stratified random sample of individuals aged 65 years and over in UK, Chaplin et al.⁽¹⁴⁾ found that around 57% of the participants had at least one gastrointestinal (GI) symptom and individual symptom and symptom complexes affected up to 32% of the sample. However, only one-quarter of these men had sought medical advice from their GP in the previous year while approximately one-third of the participants with new onset of symptoms had sought medical advice for rectal bleeding, abdominal pain and for change in bowel habit. In their cross-sectional study on the knowledge, behaviour, and experiences of adults in regards to potential symptoms of CRC in a random population in New South Wales, Australia, Cockburn et al.⁽¹¹⁾ observed that women were more likely than men to know at least one symptom (adjusted prevalence ration 1.19, 95% CI=1.12–1.28). Nevertheless, women were not more likely than men to seek medical advice for their own symptoms in their study. Eslick et al.⁽¹⁰⁾ found no statistically significant difference in men and women in terms of seeking help for rectal bleeding or other symptoms (48% vs. 52%; $p=0.58$) in their study on a random sample from New South Wales representative of Australian population. On the other hand, Courtney et al.⁽³⁸⁾ observed that inconsistent with previous literature, in their community-based study on Australian population, men were more likely to seek help than women (OR for women 0.45; $p=0.045$). In contrast in the hospital-based study of Australians diagnosed with CRC in South Australia, Young et al.⁽⁵⁴⁾ reported that men were more likely than women to experience a ‘patient-related delay’ in the diagnosis of cancer than women. However, given that the incidence and mortality of CRC is higher among men than women as reported in Section 1.1.3 in this thesis based on existing literature^(36, 66–70), the current research focused exclusively on men’s help-seeking behaviours in regards to lower bowel symptoms.

1.1.4 Gender differences: risk of CRC is higher in men

Men are at higher risk of developing CRC and have a worse prognosis compared to women^(36, 55, 66–71) (Appendices 1.1 and 1.2). Regula et al.⁽⁷²⁾ reported male sex to be an independent predictor of late-stage cancer at diagnosis. At all ages, men are more likely to be diagnosed with CRC. In their study on people diagnosed with CRC between 2000 and 2003 (74,111 men and 72,290 women in the United States from National Cancer Institute’s Surveillance, Epidemiology and End Results (SEER) Programme), Brenner et al. observed

that the average age of diagnosis for men was 4–8 years younger than for women⁽⁷³⁾. The 10 year cumulative mortality from CRC was also higher among men than among women in the 50–75 years age group in their study. Studies of screening colonoscopy in asymptomatic people report that the proportion of men with invasive malignancy in the age range of 55–74 years is much higher than in women (1% vs. 0.1%)^(74,75). Men diagnosed with IBD have been reported to have a 60% higher risk of cancer than women diagnosed with the same disease⁽⁷⁶⁾. In contrast, women have been reported to have a lower CRC-related mortality rate and an improved post-surgery survival rate compared to men.

McArdle et al.⁽⁶⁸⁾ reported a higher overall 5 year survival in women compared with men in all age groups (36.7 in men vs. 49.5 in women; $p < 0.01$) as well as higher cancer specific survival (50.4 in men and 57.1 in women; $p < 0.05$) 65–74 year age groups. They also observed higher proportion of females than males with Duke's Stage A (76.9 vs. 65.3; $p < 0.05$) and B (57.1 vs. 52.9; $p < 0.05$) cancer. The survival rates were higher in women ($n = 1594$) than in men ($n = 1606$) for both colon and rectal cancer in their study⁽⁶⁸⁾. Similar observations were made by Koo et al.⁽⁷⁷⁾. In their study of 2050 consecutive CRC patients from the cancer registry, the authors reported that women ≤ 50 years of age had a significantly higher overall survival (hazard ratio [HR] 0.46, 95% CI 0.25–0.86; $p = 0.01$) than young men independent of age, grade and stage of cancer or emergency surgery as well as significantly higher cancer specific survival (HR 0.46, 95% CI 0.25–0.85; $p = 0.01$)⁽⁷⁷⁾. On the other hand, older women (≥ 50 years) had worse survival compared to males in their study. Similar results were observed by few other studies in regards to better age specific overall survival rate in younger women than younger men^(73, 78, 79). Brenner et al.⁽⁷³⁾ reported higher age-adjusted mortality (as deaths per 100,000 person years) from CRC among men than among women in several countries such as United States (13.7 vs. 19.5), Australia (17.4 vs. 11.2), Canada (14.6 vs. 19.60, France (15.8 vs. 9.0) and Germany (18.2 vs. 11.7) for the year 2001. A discussion of the biological causes and other factors associated with higher CRC incidence and mortality in men compared with women is beyond the scope of this thesis.

The incidence of CRC can be reduced through primary and secondary prevention methods in both men and women; nevertheless, there are apparent gender differences in knowledge of, and awareness about, bowel symptoms. Ramos et al.⁽²⁴⁾ found that men had less knowledge about the symptoms of CRC than women, and they were also less aware about the significance of lower bowel symptoms (such as bloody stools and change in bowel habit), which are the same as seen in CRC. Such findings were also observed in other international studies, where men were reported to have less knowledge about CRC than women⁽⁸⁰⁾.

Therefore, the focus of the current study was on the help-seeking behaviour of men in regards to lower bowel symptoms.

1.2 Overview of the thesis

1.2.1 Aim

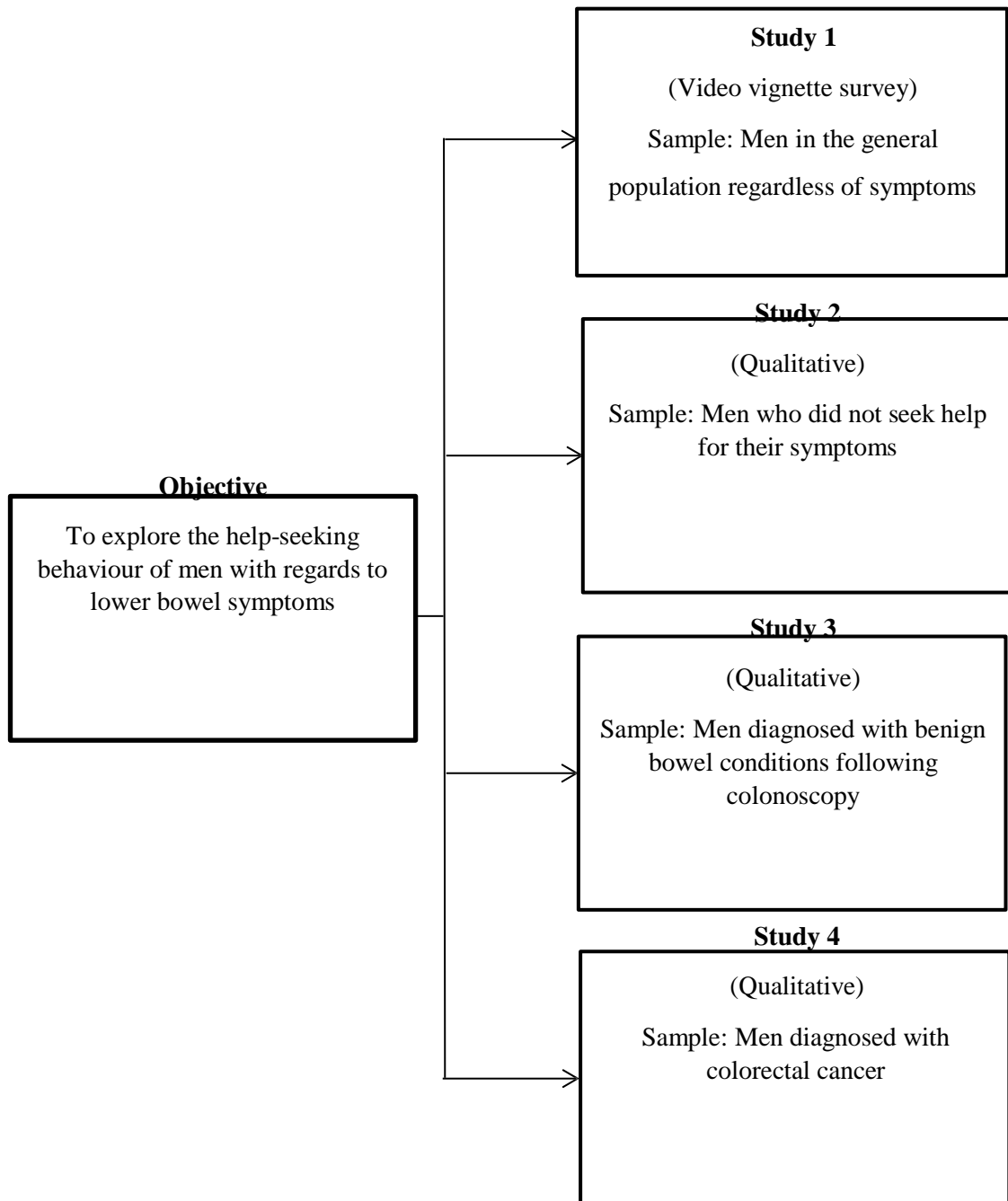
The overarching aim of this research was to study the help-seeking behaviour of men in Western Australia (WA), Australia's largest state with regards to lower bowel symptoms, and to explore the factors that may affect their decision to seek medical help.

1.2.2 Thesis outline

The rate of progression of lower bowel pathology from pre-malignant to malignant spans a period of up to 20 years^(70, 81). To explore men's help-seeking behaviour at different points in the trajectory of the disease, this thesis has been structured into four distinct studies—each with a different objective.

Study 1 was a web-based video vignette survey aimed at exploring how men would advise other men in regards to their lower bowel symptoms. Studies 2–4 aimed at exploring the help-seeking behaviour of men with first-hand experience of lower bowel symptoms. The objective of these three studies (studies 2–4) was to collect qualitative information from men at different stages of the disease and/or help seeking. Study 2 aimed to explore the help-seeking behaviour of men experiencing lower bowel symptoms but not seeking medical advice for these symptoms. Study 3 aimed to explore the help-seeking behaviour of men diagnosed with benign bowel pathology or chronic colorectal conditions, while Study 4 aimed at exploring the help-seeking behaviour of men diagnosed with CRC (see Figure 1.1).

Figure 1.1: Schema of the thesis



1.3 Research objectives and methods

The objectives and methodology of the four studies are outlined below.

1.3.1 Study 1

Objectives: Study 1 aimed to explore how men would advise other men with lower bowel symptoms. A secondary objective was to explore the factors (psychosocial, clinical and demographic) that may affect men's decisions when they advise other men to seek help for their symptoms.

Sample: A purposive sample of adult men (aged 18 years and above) (n=408) was recruited to this study. The sample was representative of adult men in the WA population. The participants were recruited from the general population regardless of their experience of lower bowel symptoms.

Methods: The data in Study 1 were collected via an online survey comprising responses to viewing video vignettes. A set of 28 video vignettes portraying men with different combinations of lower bowel symptoms were developed. The vignettes were hypothetical scenarios of men portraying lower bowel symptoms and wondering what they should do about those symptoms. Each participant watched eight randomly selected vignettes from the set of 28. The Health Belief Model (HBM) was used as a theoretical framework for this study.

A group of experts comprising five GPs reached consensus regarding which vignettes warranted medical consultation. The participants were invited to watch the vignettes and answer the following questions (dependent variables):

- i. Should the person in the vignette seek professional health advice?
- ii. Which health professional should he seek advice from?
- iii. How urgently should he seek advice?

Thereafter, the participants were asked a set of questions based on the five domains of the HBM: severity of symptoms, susceptibility to disease, benefits of and barriers to seeking advice, and confidence in a GP. The questions were based on a five-point Likert scale ranging from 'strongly disagree' to 'strongly agree'. The survey also collected demographic data from the participants.

Each participant answered the questionnaire for each of the eight video vignettes. A total of 3264 (408 participants x 8 vignettes) observations were collected. The data were analysed using the generalised estimating equation (GEE) model (logistic regression) to control for the correlations between the responses on multiple vignettes from each participant.

The participants' responses were benchmarked against the responses obtained from the expert panel. The results outlined the participants' responses to each of the dependent variables and provided information on the various factors that affected their decision to advise help seeking.

1.3.2 Study 2

Objective: To explore the barriers to help seeking among men who did not seek medical advice for their lower bowel symptoms.

Sample: A convenience sample of men (n=13) in WA was recruited from the general population through media advertisement.

Study design and methods: Qualitative semi-structured and open-ended interviews were conducted over the telephone. Andersen's Model ⁽⁷⁾ was used as the theoretical framework in Study 2 to develop the interview schedule. The model encompasses the stages of delay or the time interval between the onset of symptoms and help seeking. The details of the model have been discussed in detail in Section 4.3.1 of the thesis. As the participants in this study did not seek help for lower bowel symptoms, the questions were based on the first four domains of the model: appraisal delay, illness delay, behavioural delay and scheduling delay. The last stage of the model, treatment delay, was excluded from the interviews. The interviews continued until no new information emerged. The data were analysed thematically with themes representing barriers to help seeking.

1.3.3 Study 3

Objective: To explore the barriers and facilitators to help seeking among men diagnosed with benign colorectal conditions following a colonoscopy.

Sample: A convenience sample of men (n=19) aged between 30 and 78 years was recruited from the outpatient clinic of a large tertiary care hospital in WA over a five-month period (February 2013–July 2013). The interviews were conducted prior to diagnosis, and the diagnosis was confirmed after colonoscopy.

Study design and methods: In-depth semi-structured interviews were conducted. The interview comprised questions about the participants' symptoms and help-seeking experiences. These questions were based on the literature and guided by the theoretical framework. The five domains of Andersen's Model ⁽⁷⁾—appraisal delay, illness delay, behavioural delay, scheduling delay and treatment delay—were used to guide the data collection and analysis. The data were collected via face-to-face interviews and were analysed thematically with themes representing the barriers and facilitators to help seeking among these men.

1.3.4 Study 4

Objective: To explore the help-seeking behaviour of men diagnosed with CRC.

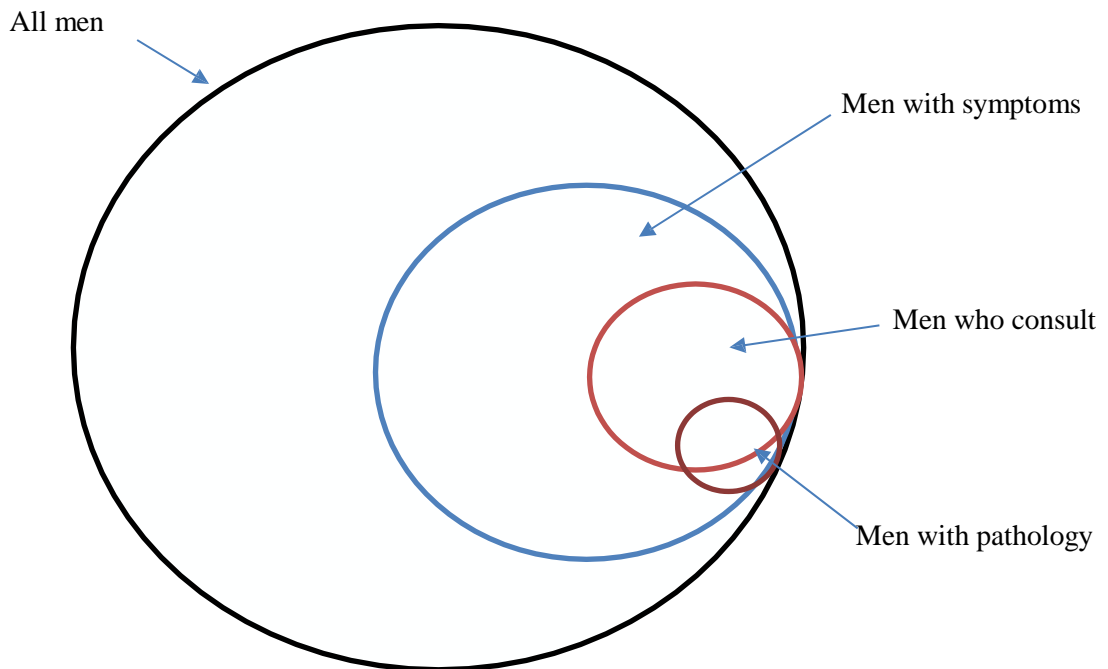
Sample: The participants included 20 adult men living in WA aged between 27 and 87 years, who had been diagnosed with CRC within three months from the date of the interview. The sample was selected from a CRC clinic at a large tertiary care hospital in WA over a five-month period (February 2013–July 2013). Participants were interviewed post-diagnosis and prior to their treatment.

Study design and methods: In-depth semi-structured interviews were conducted comprising questions about the participants' symptoms and help-seeking experiences. Questions were also asked about any delays in referral or the scheduling of a colonoscopy. The five domains of Andersen's Model ⁽⁷⁾—appraisal delay, illness delay, behavioural delay, scheduling delay and treatment delay—were used to guide the data collection and analysis. The data were analysed thematically and presented as factors facilitating and impeding help seeking for symptoms of CRC.

1.3.5 Summary

The results of the four studies represented a trajectory of help-seeking behaviours of men from symptom through to diagnosis of CRC (Figure 1.2).

Figure 1.2: Overview of the trajectory of help seeking from symptoms to CRC diagnosis



1.4 Organisation of the thesis

This thesis has been organised into seven chapters comprising four studies, as outlined below. The first chapter provides the background to this research and the overview of the thesis. Chapter 2 is a literature review of the help-seeking behaviours with regards to lower bowel symptoms using a gender lens. Chapters 3–6 relate to the four individual studies conducted as part of this thesis. Chapter 3 describes the vignette survey conducted with men in general population. Chapters 4, 5 and 6 describe the qualitative studies conducted with men who did not seek medical advice, those who were diagnosed with benign or chronic bowel conditions and those diagnosed with CRC respectively. Chapter 7, which is the last chapter of this thesis, includes the discussion of the findings, limitations of the research, implications of the findings and conclusions. Table 1.1 outlines the organisation of the thesis.

Table 1.1: Organisation of the thesis

Chapter	Title
Chapter 1	Introduction: This chapter includes the background to the study and an overview of this thesis.
Chapter 2	Literature review: This chapter reviews the literature for help-seeking behaviours with regards to lower bowel symptoms.
Chapter 3	Study 1 To determine the factors that may impact the decision to seek medical advice in men with lower bowel symptoms: a web-based video vignette survey.
Chapter 4	Study 2 To explore the barriers to help seeking in men experiencing lower bowel symptoms and not seeking medical advice: a qualitative study.
Chapter 5	Study 3 To explore the help-seeking experiences of men diagnosed with benign bowel conditions: a qualitative study.
Chapter 6	Study 4 To explore the help-seeking behaviour of men diagnosed with CRC: a qualitative study.
Chapter 7	Discussion of the results and limitations of the study, conclusions, implications and recommendations.

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Chapter 2: Literature Review

Study of help-seeking behaviours with regards to lower bowel symptoms using a gender lens: a literature review.

Publications

A section of the literature review has been published in *Quality in Primary Care*, and the abstract has been published in the supplement issue of the *European Journal of Cancer Care* as shown below

Citations

Research paper

Oberoi DV, Jiwa M, McManus A, Hodder R. Colorectal cancer: applying a gender lens. *Quality in Primary Care*. 2014; 22(2):71–9.

Abstract

Oberoi DV, Jiwa M, McManus A, Hodder R. Help seeking behaviour for colorectal cancer (CRC) symptoms: applying a gender lens. *European Journal of Cancer Care*. 2014; 23:4.

2.1 Summary

Objective: The objective was to review the literature for behavioural factors influencing patient delay in seeking help for lower bowel symptoms using a gender lens.

Methods: A literature search was conducted using databases such as MEDLINE, PubMed, CINAHL Plus, EMBASE and PsycINFO (1993–2013). Various search terms were used, including rectal bleeding, prevalence, colorectal cancer, consultation, help seeking, gender differences and men. A systematic methodology was applied, including systematic data extraction and narrative synthesis. The factors influencing the delay in seeking medical advice were analysed within the framework of Andersen’s Model of Total Patient Delay.

Results: Thirty-two studies were included in the review. All studies except four were quantitative. There was some evidence that men were more likely to delay seeking medical advice compared with women; nevertheless, limited studies have focused specifically on men’s help-seeking behaviour for lower bowel symptoms. Several behavioural and demographic factors were associated with low rates of help seeking. Men were more likely to delay seeking medical advice for lower bowel symptoms.

Conclusions: Given the higher risk of CRC in men, it is important to explore men’s understanding of the seriousness of lower bowel symptoms and the factors influencing their help-seeking behaviour for these symptoms.

2.2 Background

2.2.1 Help-seeking behaviour: Australian perspective

There is limited literature on the help-seeking behaviour of the Australian population in regards to lower bowel symptoms. In a South Australian study, in a consecutive sample of patients diagnosed with CRC, Young et al. ⁽¹⁾ explored reasons for delayed diagnosis and for the delay in seeking medical advice for lower bowel symptoms. They reported that men were more likely to experience ‘patient-related delay’ in cancer diagnosis than women. The reasons cited by the participants in this study for delayed presentation to a GP were the attribution of symptoms to conditions such as haemorrhoids, belief that the symptoms would clear up spontaneously, and a desire to wait to seek advice until the symptoms exacerbated. Two participants were reluctant to undergo investigations advised by their GP after their initial visit ⁽¹⁾.

In their survey on the help-seeking behaviour of an adult Australian population (n=1332) in regards to the potential symptoms of CRC, Cockburn et al. ⁽²⁾ found that less than 50% of the population was aware of all of the symptoms that could be indicative of CRC. The majority of the population knew only rectal bleeding as a symptom indicative of cancer. Nearly one in three Australian adults who had experienced lower bowel symptoms delayed seeking medical advice for more than three months or did not seek advice at all. The primary reasons for delayed help seeking were similar to those reported by Young et al. ⁽¹⁾ such as the attribution of rectal bleeding to haemorrhoids, and the perception that the symptoms did not warrant medical consultation. Some people did not want their family to worry about their symptoms, and others believed that a GP would not be able to help with their symptoms. Nearly 2% of the study population was reticent to seek help, believing that the tests would be embarrassing and/or unpleasant ⁽²⁾. Women were more likely to be aware of the symptoms of CRC than men, although they were not more likely to seek advice than men. Knowledge levels were directly related to people's education levels and their beliefs about the benefits of the early detection of cancer. Cockburn et al. ⁽²⁾ suggested that media campaigns aiming to improve people's knowledge about the risks of cancer had not been very successful in influencing people to seek timely medical advice. In light of their findings, they advocated for the need for more intensive public education campaigns focused on addressing negative perceptions of cancer and people's lack of knowledge of the risks of cancer associated with lower bowel symptoms ⁽²⁾.

In their observational study (n=1996) on the process of cancer diagnosis in Queensland, Lynch et al. ⁽³⁾ observed that the majority of patients diagnosed with CRC were symptomatic. However, patients who experienced symptoms such as change in bowel habit, abdominal pain and those who had private health insurance were less likely to delay seeking help for their symptoms. Likewise, older patients were more likely to seek timely help than younger patients. Delays in help seeking were reported in people presenting with symptoms such as rectal bleeding, unexplained weight loss, nausea/vomiting, tiredness, increased flatulence and loss of appetite in their first consultation with a GP. In another Australian study, Eslick et al. ⁽⁴⁾ observed that nearly one in three people experiencing rectal bleeding had sought medical advice, although they found no gender differences in healthcare seeking. A 2012 Australian population-based study by Courtney et al. ⁽⁵⁾ found that nearly one in five Australians had never consulted a GP for rectal bleeding or for change in bowel habit. Courtney et al. ⁽⁵⁾ also reported that people who had ever been advised by a health professional for screening were more likely to seek advice. The triggers for early (<2 weeks of symptom onset) help seeking for rectal bleeding were mainly the belief that the symptoms were serious, and the opportunity to discuss the symptoms while visiting a GP for other

health issues. People who had private health insurance were nearly four times more likely to seek early advice than those without private health insurance ⁽⁵⁾. In regards to change in bowel habit, people with lower household incomes, those within a healthy BMI range (18.0–24.9) and those who had discussed their family history of CRC with a GP in any of their previous visits were more likely to seek medical advice. Likewise, those who had been informed of the risk of CRC by a GP in a previous visit and those who had persistent symptoms were likely to seek advice early (<4 weeks). Based on their findings, Courtney et al. emphasised the need to improve people’s knowledge of the potential risks associated with persistent lower bowel symptoms and the benefits of timely help seeking. However, findings from past studies cast doubt on the role of improving people’s knowledge of symptoms and encouraging them to seek help at an opportune time. Currently, there is mixed evidence on the translation of increased knowledge of CRC symptoms into timely help seeking for the early diagnosis of cancer. Some studies have found a positive association between knowledge of symptoms and help seeking ⁽⁶⁾, and a negative association between knowledge and negative perceptions of cancer, implying that improving knowledge of the symptoms or disease may influence help seeking ⁽⁷⁾. However, a few other studies have found no association between knowledge and help seeking ^(2, 8, 9).

The similar findings in these studies suggest that there has not been any major change in the help-seeking behaviour of Australians regards lower bowel symptoms over the past 12 years.

2.2.2 Overview of men’s help-seeking behaviour in general

In past studies, men have reported a delay in seeking timely medical advice for their symptoms ^(10–14). Although there is a higher rate of premature death among men, they are less likely to see a GP than women ⁽¹⁵⁾. Men have also reported a delay in seeking help until the symptoms begin to interfere with their normal lives ^(11, 12, 16–18). In their theory on the perception of masculinity and its influence on men’s health, Courtney ⁽¹⁹⁾ reported that men have lower health literacy than women in general, and they are less knowledgeable about specific diseases and risk factors ⁽¹⁹⁾. Similar views have been echoed by other studies in regards to lower bowel symptoms ^(7, 20).

In Australia, mortality rates are considerably higher among men compared to women (in the 25–64 year age group) from chronic diseases such as ischaemic heart disease and cancer ⁽²¹⁾. Data from General Practice Activity in Australia for 2012–2013 suggest that females made 56.7% of GP visits compared to 47.3% for males ⁽²²⁾. Aoun and Johnson ⁽²³⁾ observed that nearly two-thirds of the male population in the rural southwest of WA (geographically the largest state in Australia) did not seek timely medical help because they did not consider

their symptoms serious enough to warrant consultation, although there were no major problems in regards to accessing a GP.

Similar findings have been reported from other international studies^(10–14, 24, 25). In the United States (US), men are known to have a 43% higher age-adjusted death rate than women, and they tend to die 5.4 years earlier⁽²⁶⁾. Additionally, for every 16 male deaths before the age of 50, there are only 10 female deaths^(27, 28). The 2004 Health Survey in the US⁽²⁹⁾ reported that men under 65 years of age were almost twice as likely as women in the same age group (21% vs. 11%) to have no usual source of healthcare, and they were also less likely to have health insurance. In addition, men of all ages—particularly between 18 and 54 years—were less likely than women to seek medical help⁽²⁹⁾. Sandman et al.⁽³⁰⁾ reported that even after controlling for pregnancy-related visits, women in the US were nearly twice as likely as men to seek preventive health (33% vs. 19%), and they had a higher chance of visiting a doctor regularly than men. The report also stated that 24% of men had not visited their physician in the past year compared to 8% of women and only one-fifth of men were willing to seek timely medical advice in the event of illness⁽³⁰⁾.

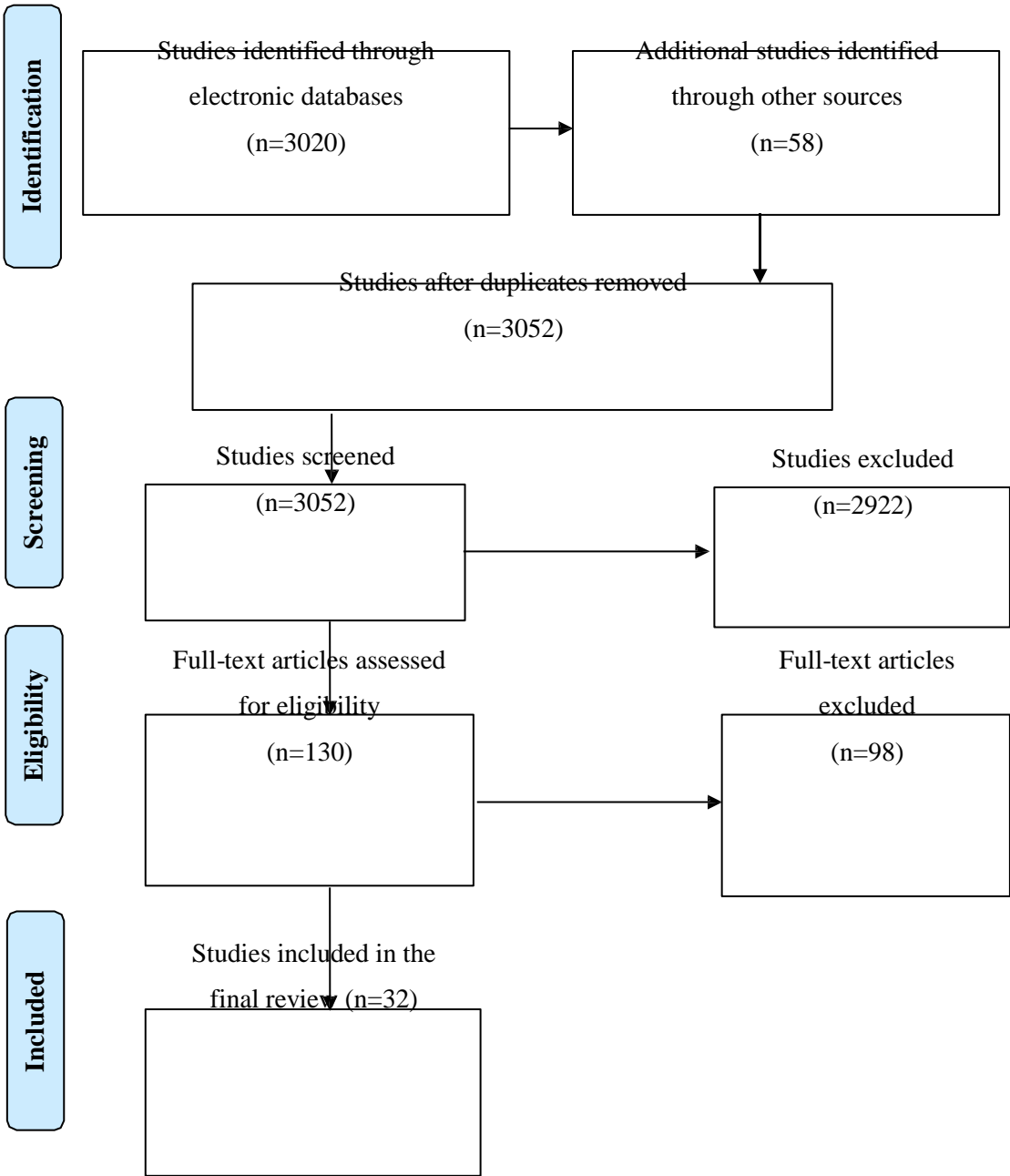
2.3 Objective of the literature review

To address the literature gap in regards to differential help-seeking behaviour among males and females, this chapter reviews the literature in relation to factors influencing the decision to seek medical advice for lower bowel symptoms using a gender lens.

2.4 Methods

A literature search was conducted using the MEDLINE, PubMed, CINAHL Plus, EMBASE and PsycINFO (1993–2013) databases with various combinations of search terms, including rectal bleeding AND prevalence, rectal bleeding AND colorectal cancer, rectal bleeding AND consultation, rectal bleeding AND help seeking, colorectal cancer AND gender differences, and colorectal cancer AND men. The references and bibliographies of the included studies were also reviewed. Two reviewers independently screened the abstracts of all relevant citations before inclusion. When there was a conflict between the reviewers about the inclusion of a paper, a third reviewer's opinion was sought. Common themes and concepts across the included studies were identified via a narrative synthesis of the findings. Patient delay was defined as the time interval between the onset of symptoms and the first medical consultation.

Figure 2.1: PRISMA flowchart for the flow of studies into the literature review of factors influencing the decision to seek medical advice for lower bowel symptoms



The search was limited to studies published in the past 20 years, with nearly 50% published in the past 10 years. A total of 3020 published studies were obtained using various combinations of search terms, of which only 130 (4.3%) met the inclusion criteria. Studies that did not focus on help-seeking behaviours with regards to lower bowel symptoms were excluded. After screening the full-text articles, studies that only investigated referrals or hospital-related delays in CRC diagnosis, or that focused on factors related to the uptake of screening, were excluded from the review. After further analysis, 32 studies were included in the review (see Table 2.1).

Studies that were included in the final review were those that:

- a. Focused on factors associated with the delay between the onset of symptoms and seeking medical advice regardless of CRC
- b. Had rigorous methods of data collection and analysis (quantitative and qualitative).

2.5 Results

Of the 32 studies included in the review, 15 were conducted in Europe, eight in the UK, five in Australia, three in the US and one in Canada. The majority of studies in this review were conducted with people who had CRC or those who may or may not have sought medical advice for their lower bowel symptoms mimicking CRC, and few were conducted on people with benign bowel pathology or chronic lower bowel conditions (n=2). The sample size in the studies ranged from six to 1966. Four studies were qualitative. The studies included in the review are reported in Appendix 2.1.

2.5.1 Delay interval

Patient delay ranged from one week to one year. While 14 studies focused solely on patient delay, the remaining studies (n=18) focused on patient and system delay. However, the current literature review focused on the factors associated with the delay between the onset of symptoms and the first medical consultation.

2.5.2 Gender differences in patient delay

Of the 32 studies included in this review, 17 provided information on help-seeking behaviour for lower bowel symptoms in both men and women. Of these 17 studies, nine studies reported no gender differences in help seeking^(2-4, 31-36) and others reported that men delayed more than women⁽³⁷⁻⁴¹⁾. Only one study found that women delayed more than men⁽⁴²⁾, and

one study reported a longer delay associated with men younger than 65 years and women older than 80 years ⁽⁴³⁾.

2.5.3 Factors influencing delay in seeking help

Most of the studies (n=31) identified factors that increased patient delay, and 23 studies identified factors that reduced patient delay. Some factors had a mixed effect on patient delay. The various factors associated with patient delay are summarised in Table 2.1.

2.5.3.1 These factors were evaluated using a theoretical framework, Andersen's Model of Total Patient Delay ⁽⁶²⁾. The first four stages of the model—appraisal delay (time lapse between the detection of symptoms by the patient and inferring illness), illness delay (delay occurs as the patient contemplates between consulting a medical practitioner or self-treating the illness), behavioural delay (delay in making an appointment with a GP) and scheduling delay (time lapse between making an appointment and the first medical consultation)—were used to classify the reasons for delay into four categories. The fifth stage of the model, treatment delay (time between the first medical consultation and the initiation of treatment), was beyond the scope of this study, which focused exclusively on patient delay. The details of the Andersen's model are provided in Section 4.3.1. In their systematic review of the studies focussing on pathways to cancer diagnosis using Andersen's model, Walter et al. ⁽⁶³⁾ confirmed that only few studies (n=8) had utilised the theoretical framework based approach. Nevertheless, the authors emphasised that there was strong evidence in favour of the stages of delay originally identified by Andersen's model, between detection and appraisal of symptoms, seeking medical advice, and the diagnosis and treatment of cancer. Appraisal delay

Several factors were associated with peoples' appraisal of their symptoms as an illness. There was a delay in seeking help when symptoms were attributed to a minor illness and believed to be part of the ageing process ^(1, 40, 44, 45), and when people failed to recognise symptom severity ^(2, 38, 46–50).

The non-specific nature and moderately high prevalence of lower bowel symptoms in the general population may lead to a delay between symptom onset and the initiation of treatment ⁽⁵¹⁾. Specific symptoms such as rectal bleeding and abdominal pain were associated with less delay in seeking medical advice than non-specific symptoms such as change in bowel habit and unexplained weight loss ^(35, 49). Lack of concern and knowledge of the risks associated with the symptoms, or self-treatment prior to seeking professional medical advice, increased the delay in some studies ^(2, 52). A lack of awareness of being at-risk led to a misinterpretation of symptoms, which further delayed diagnosis and led to trivialisation ^(2, 45).

Cockburn et al. ⁽²⁾ found that two in three Australian adults were aware of rectal bleeding as a symptom of CRC; however, less than 50% had knowledge of other potential symptoms of cancer. Carlsson et al. observed that only 1.5% of the population warranted seeking medical help for change in bowel habit ⁽⁵³⁾. In some instances, the nature of the bleeding also played a role in determining whether advice was sought, as people consulted for bleeding in the toilet pan more often than for blood on toilet paper ⁽⁵⁴⁾.

There were shorter delays in seeking help when the symptoms occurred more frequently, were severe or affected a person's daily life ^(32, 48, 49). The delay was especially shorter when pain, vomiting and intestinal obstruction were the initial presenting symptoms ⁽⁴²⁾.

2.5.3.2 Illness delay

A number of factors were associated with patients' preference for self-treatment over seeking medical advice. A few studies found that patients in younger age groups were more likely to delay ^(31, 55), whereas others found no relationship between age and help-seeking behaviour ^(32, 35). Low socio-economic status and a lack of additive private health insurance were other factors that may have contributed to the delay in seeking help and treatment ^(5, 33, 55). Bain et al. ⁽⁴⁴⁾ observed that people who resided in rural areas were more likely to delay seeking advice than those who resided in urban areas; however, Robertson et al. ⁽⁴⁹⁾ observed no such difference.

2.5.3.3 Behavioural delay

A number of factors were associated with the delay in making an appointment with a GP. The worsening of symptoms or the appearance of additional symptoms led to the reinterpretation of symptoms by people and helped in inferring the illness in some cases and a large number of people delayed seeking help because they feared unpleasant or embarrassing investigations, and they hoped for the spontaneous resolution of symptoms ^(52, 55). Knowing a person with CRC within the family or among friends was observed to reduce patient delay ⁽⁵⁵⁾.

Cognitive–emotional factors such as fear of pain, lack of perceived risk for CRC, concerns about the examination of private body parts and bowel preparation associated with invasive procedures may further discourage people with symptoms from seeking early medical attention ⁽⁵⁶⁾. Fear of cancer diagnosis or poor prognosis ^(46, 48, 55), and investigations and consequences of treatment ^(48, 55), also played a major role in preventing people from seeking timely medical help. Ramos et al. ⁽⁴¹⁾ observed that women mentioned their symptoms directly to their GP, whereas men volunteered to mention their symptoms during medical

consultations for other health conditions. McCaffery et al. ⁽⁷⁾ observed that increased knowledge of CRC reduced negative perceptions and encouraged timely help seeking for symptoms. Social support by lay networks such as family and friends played a major role in encouraging people to seek help ^(42, 46, 48-50).

The delay was reduced in cases where people discussed their symptoms with others or did not wait for the spontaneous resolution of symptoms ⁽⁴²⁾. Cockburn et al. ⁽²⁾ found that divorced individuals were more likely to seek help than those who were married. However, this difference could not be explained in other studies. Overall, there was no clear consensus between marital status and help seeking, as some studies observed shorter delays in married men, whereas other studies observed an increased delay ^(2, 55).

The literature also suggests that there is anxiety, hesitancy, taboos and embarrassment associated with digital rectal examination in men ⁽⁵⁷⁾. These concerns could be magnified when men are examined by a female doctor, and in those who have previously been victims of sexual abuse ⁽⁵⁷⁾. This may be a deterrent in seeking medical advice.

Table 2.1: Factors affecting patient delay

Factors that increased patient delay
<p>Demographic factors</p> <p>Educational level (low) ⁽³⁷⁾</p> <p>Younger age (<50 years) in men and older age in women ⁽⁴³⁾</p> <p>Lack of health insurance ⁽³⁾</p> <p>Low income ⁽⁵⁵⁾</p> <p>Living with spouse (rectal cancer) ⁽⁵⁵⁾</p> <p>Living in rural areas ⁽⁴⁴⁾</p> <p>Inadequate transportation facilities ⁽⁴⁴⁾</p> <p>Difficulty in visiting GP or making appointment ⁽⁴⁴⁾</p> <p>No screening advice received from the doctor ⁽⁵²⁾</p> <p>Lack of social support ⁽⁵⁵⁾</p> <p>Other factors</p> <p>Non-specific symptoms ^(1, 46, 50)</p> <p>Attribution of symptoms to benign conditions and non-recognition of symptom severity ^(1, 2, 5, 7, 46, 50)</p> <p>Attribution of symptoms to changes in diet and lifestyle ⁽⁵⁰⁾</p> <p>Fear of unpleasant investigations and or treatment ^(1, 2, 55, 46)</p> <p>Denial of cancer ⁽⁴⁶⁾</p> <p>Belief that the symptoms would resolve spontaneously ^(2, 48)</p> <p>Past history of anxiety and depression ⁽⁴⁹⁾</p> <p>Family history of cancer ⁽²⁰⁾</p> <p>Relief from OTC medications ⁽⁴⁰⁾</p>
Factors that reduced patient delay
<p>Demographic factors</p> <p>Age (>60 years) for males ⁽⁸⁾</p> <p>Retired from job ⁽²⁾</p> <p>Other factors</p> <p>Persistent symptoms ^(20, 41, 48) Blood mixed in stool ⁽²⁰⁾ Abdominal pain and discomfort ⁽⁴²⁾</p> <p>Multiple symptoms occurring together</p> <p>Trust in GP ⁽⁴⁶⁾</p> <p>Symptom disclosure to someone significant ^(42, 46)</p> <p>Knowledge about the cause of symptoms ⁽⁴⁶⁾</p> <p>Opportunity to talk to GP about lower bowel symptoms during regular visit ⁽⁸⁾</p>

2.5.3.4 Scheduling delay

People who trusted their GPs or healthcare practitioners and believed that they could help were more likely to seek timely help ^(32, 42, 46). Some people were not confident in discussing their symptoms with a GP, were worried about the outcome or procrastinated seeing a GP because of a lack of time or other commitments ^(2, 52). A few were too busy to visit a GP, had difficulty making an appointment or believed that consulting a GP would be unpleasant or embarrassing ⁽⁵²⁾.

2.6 Discussion

A feature of this literature review was the use of a theoretical framework to classify the factors associated with patient delay. The current review expanded on previous reviews of patient-related delays, and most patient-related factors and results were consistent with the previous reviews ^(58–61). In addition, the current review focused on gender differences in help-seeking behaviour for lower bowel symptoms. One of the major reasons for patient delay was the failure to appraise the symptoms as illness because of a lack of adequate knowledge of the risk of CRC in people with persistent lower bowel symptoms. This is in line with Andersen's Model of Total Patient Delay. ⁽⁶²⁾, which suggested that appraisal delay was the major component of the entire model of patient delay. In their study, de Nooijer et al. ⁽⁴⁶⁾ mentioned that denial of illness could result in patient delay. However, other behavioural and cognitive–emotional factors were also responsible for longer delays in our review. Fear of poor prognosis may also prevent people from seeking help. The fear of being regarded as neurotic, a hypochondriac or a time-waster by a GP was also associated with men's poor help-seeking behaviour ⁽⁵⁸⁾.

About 50% of the studies in this review that provided information about help-seeking behaviour with regards to lower bowel symptoms either did not focus on, or were equivocal about, the role of gender in help seeking. Nearly one in three studies focused on gender differences in help-seeking behaviour, and men were more likely than women to delay seeking medical advice. However, gender-specific reasons for patient delay were not evaluated in these studies. Several factors have been postulated for men's poor help-seeking behaviour compared with women. Smith et al. ⁽⁵⁸⁾ identified stoicism as one of the reasons for men's reticence, as help seeking was portrayed as a sign of weakness. In this review, the evidence for men's poor help-seeking behaviour mostly stems from the quantitative studies, as only one qualitative study found that men delayed more.

2.7 Conclusion

There is some evidence that men delay seeking timely medical help for their symptoms more than women. The results of this literature review indicate further research into men's help-seeking behaviour with regards to lower bowel symptoms is warranted. Given that men are biologically more susceptible to bowel cancer than women; it may be useful to facilitate a change in attitude towards seeking early attention to symptoms to encourage men to seek timely medical advice.

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Chapter 3: Do Men Know Which Lower Bowel Symptoms Warrant Medical Attention? A Web-based Video Vignette Survey of Men in WA (Study 1)

Publication

This study has been published in the *American Journal of Men's Health* as shown below.

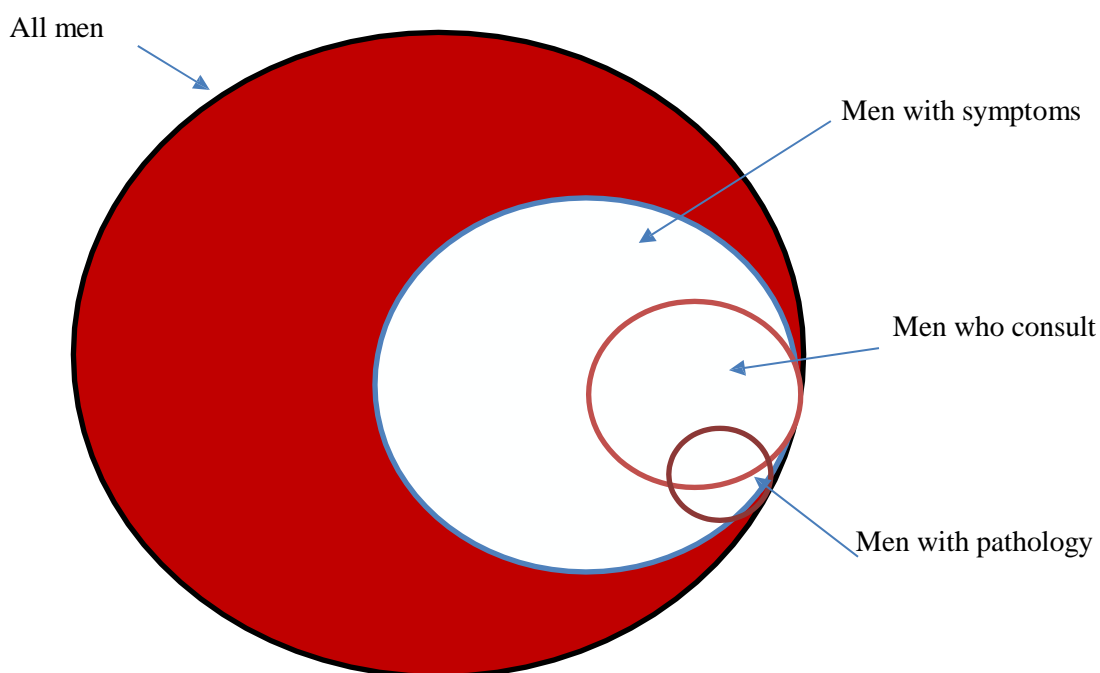
Citation

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3.1 Summary

Study 1 targeted men in the general population whether or not they had experienced lower bowel symptoms. It aimed to explore how men in the general population would advise other men about seeking help regarding lower bowel symptoms. The four circles in Figure 3.1 represent the four studies conducted as part of this thesis, with each study representing a different stage in the trajectory from (lower bowel) symptoms to diagnosis of CRC. Study 1 is the coloured circle in Figure 3.1.

Figure 3.1: Schema of the thesis—Study 1 (highlighted)



Background: Lower bowel symptoms are common in the general population and can be associated with both benign conditions and life-limiting conditions, including CRC.

Objective: Study 1 aimed to explore how men in the general population would advise other men about seeking help with regards to lower bowel symptoms, and to determine the factors that may influence decision to seek help.

Methods: A sample of WA men aged 18 years and above was recruited for the study. A total of 28 video vignettes were developed. Each participant completed eight randomly assigned video vignettes from the set of 28. The vignettes presented old or young men with different symptoms or symptom combinations (rectal bleeding, diarrhoea, unexplained weight loss) of varying duration (3 days or 3 weeks). Participants were asked whether the person in the vignette should seek health advice, and if so, where he should seek advice. Subsequently, the

participants answered a set of questions based on the Health Belief Model (HBM). A Generalised Estimating Equation (GEE) model was used to identify the relative importance of the HBM, the symptom profile portrayed in the vignette and the demographic profile of the participant to the decision to seek advice from a health professional. Three different GEE models were developed with three dependent variables respectively for seeking advice for lower bowel symptoms, seeking advice from GP and seeking advice urgently (within a week). Participants' responses were compared with those of expert panel comprising five GPs. Independent predictors for agreement between the participants and the expert panel were identified. Results were presented as odds ratios, with 95% CI. A p value of ≤ 0.05 was considered significant.

Results: Four hundred and eight participants (response rate 51%) answered eight vignettes each resulting in a total of 3264 vignette observations. Participants younger than 50 years, those who were not tertiary educated and who had lower incomes, and those living in regional or remote areas were less likely to agree with the expert panel with regards to seeking help from a GP ($p < 0.05$). Participants who visited their GP less frequently or believed that visiting a GP was time-consuming were also less likely to agree with the expert panel ($p < 0.05$). With regards to clinical symptoms, the respondents were more likely to recommend help seeking for vignettes with symptoms lasting for three weeks compared to three days. There was a trend to consider unintentional weight loss and diarrhoea as minor symptoms not necessitating medical attention ($p < 0.05$).

Conclusions and implications: Men's decision to advise other men about their lower bowel symptoms in agreement with the expert panel, were associated with their demographic characteristics and the clinical symptoms presented in the vignettes. There is a need to improve public awareness among men about the need to seek timely medical advice for lower bowel symptoms in primary care. The importance of the early presentation of persistent lower bowel symptoms should be specifically targeted at men younger than 50 years, those with lower incomes and those residing in regional or remote areas.

3.2 Background

CRC is often symptomatic and has a high potential for curative treatment when detected at an early stage ⁽¹⁾. In contrast, late-stage presentation is associated with a poor five-year survival ⁽²⁾. Patient delays in seeking health advice are relatively more common than the healthcare system delays in the diagnosis of CRC ⁽³⁾. This information has also been highlighted in Chapters 1 and 2 of this thesis respectively. The majority of CRC patients experience lower bowel symptoms such as rectal bleeding, change in bowel habit, abdominal

pain and weight loss⁽⁴⁾; however, the rate of seeking medical advice for such symptoms is low, ranging between 14-45%⁽⁵⁻⁷⁾. These symptoms are common in the general population, and they are often self-limiting^(8,9). Knowledge about these symptoms does not always facilitate consultation. In their study on the Australian population (n=1332), Cockburn et al.⁽¹⁰⁾ observed that the awareness of these symptoms alone did not ensure timely help seeking among the participants. Hashim et al.⁽¹¹⁾, similarly, found no association between knowledge of cancer symptoms and early presentation of rectal bleeding, and highlighted a gap between knowledge and help-seeking behaviour in a Malaysian population. A recent Danish study by Pederson et al.⁽¹²⁾ reported that CRC patients with rectal bleeding experienced longer delays in seeking medical advice than patients without rectal bleeding when adjusting for other symptoms such as change in bowel habit or abdominal pain. They also suggested that the attribution of symptoms to other common causes was not the only reason for patient delay, and emphasised the need to identify the barriers to help seeking. A study conducted on the uptake of faecal occult blood testing (FOBT) screening practices in a rural Queensland community in Australia⁽¹³⁾ reported that although rectal bleeding was recognised as a symptom of CRC by most participants, very few could identify non-specific symptoms, such as change in bowel habit, abdominal pain and unintentional weight loss, as cancer symptoms. Additionally, men were less likely to identify symptoms of CRC than women.

Adelstein et al.⁽¹⁴⁾ observed that patients who took their symptoms less seriously had a threefold higher prevalence of cancer than those who acted on their symptoms at a relatively early stage. Qualitative studies focusing on Australian men have found that the while rationalisation of lower bowel symptoms and self-medication were common practices among men and prevented them from seeking medical advice, support from female family members may play a vital role in encouraging men to seek help^(15,16). Fear of diagnosis and the cost of consulting a GP were other barriers to help seeking⁽¹⁷⁾. Patients have to bear out-of-pocket costs (nearly \$30 for a GP consultation and more than \$200 for a specialist consultation) if they consult a non-bulk-billing doctor⁽¹⁸⁾. Further, it is speculated that the proposed co-payment fee to be paid by Australians for each GP visit and diagnostic investigation, as well as the proposed increase to co-payments for prescription medications, is likely to further discourage people from seeking timely medical advice⁽¹⁹⁾. Late-stage or emergency presentation leads to poorer five-year survival and higher mortality rates⁽²⁾.

To facilitate timely help seeking among men, it is important to understand the factors that affect their decision to seek help. The literature review conducted as part of this thesis (Chapter 2) discussed various behavioural factors associated with the delay in seeking

medical advice for lower bowel symptoms. The current understanding of help-seeking behaviour for lower bowel symptoms is largely based on retrospective studies highlighting retrospective recall of symptoms and time intervals from symptom onset to help seeking^(6, 10, 19, 20). Such information may be subject to memory-recall bias, as it may be difficult to remember the exact timing of vague and non-specific symptoms and the health actions taken in response to the symptoms^(10, 21).

Study 1 in this thesis aimed to explore the factors that may affect how men would advise other men with regards to their lower bowel symptoms through the use of standardised case vignettes.

3.3 Methods

3.3.1 Theoretical framework

The HBM was used as a theoretical framework in this study. The HBM purports that the decision to commit to a recommended health action (seek medical advice) is associated with the perception of the severity of symptoms, susceptibility to the disease, perceived benefits of the action, absence of barriers to the action and confidence in the GP or family physician⁽²²⁾. The model also proposes that demographic variables (i.e., age, sex or ethnicity), socio-psychological variables (i.e., personality or social class) and structural variables (i.e., knowledge about the disease or personal experience with a condition) may indirectly influence health-related behaviours by affecting an individual's perception of susceptibility, severity, benefits and barriers^(23, 24). The HBM has been used in studies of behaviour following a diagnosis of CRC^(25, 26); however, the application of the model to predict the early presentation of symptoms in primary care needs to be explored⁽¹¹⁾. As the HBM was originally developed to explain preventive behaviours, it was considered an appropriate model for the current research⁽²⁷⁾.

3.3.2 Study design and participants

In this case vignette-based study, participants were recruited from the general population in WA through a research recruitment agency, and the data were collected between August and October 2012. The potential participants were approached by the recruitment agency, and those who were willing to participate were included in the study. Eligible participants had to be men, aged 18 years or older, be able to communicate in English, have access to the internet and be willing to complete a self-administered online questionnaire. The sample was selected in a purposive manner so as to closely resemble the WA population with regards to age, income, educational and employment status, relationship status, and country of birth

(consistent with WA Census 2011)⁽²⁸⁾. The participants gave informed consent before starting the survey. The focus of the study was exclusively on males, as men have a higher biological risk and prevalence of CRC compared to women, and they are somewhat more likely to delay seeking medical advice for the primary symptoms of CRC^(1, 29-33), as has been discussed in Chapters 1 and 2 of this thesis.

Based on the number of explanatory variables (n=20), and to achieve a power of 80% to detect variables exhibiting a moderate effect size, with $\alpha=0.05$, a minimum sample size of 156 participants was required⁽³⁴⁾. The explanatory variables were: clinical variables presented in the case vignettes (see Table 3.1), demographic variables (see Appendix 3.1—Section 1a) and the five domains of the HBM (see Appendix 3.1—Sections 1b and 2). To be consistent with the HBM, which was used as a theoretical framework, demographic variables such as age, income, educational and employment status, relationship status, country of birth and/or duration of stay in Australia, residence (metropolitan or regional/remote area), and private health insurance were used as covariates.

Table 3.1: Five binary clinical variables describing each vignette in Study 1

Variable	Condition
1. Age of the person in the vignette	35 or 65 years
2. Duration of symptoms	Three weeks or three days
3. Rectal bleeding	Present or absent
4. Change in bowel habit	Present or absent
5. Unintentional weight loss	Present or absent

3.3.3 Use of vignettes

Vignettes (hypothetical scenarios) are useful in eliciting information about questions that may be personally intimidating, under-reported or distorted in a socially desirable direction⁽³⁵⁻³⁷⁾. Another major advantage is that the vignettes can reflect real-life scenarios while controlling for external or potentially confounding variables. Participants are invited to respond to survey questions from their own perspective or from that of the vignette character; however, answering the hypothetical scenarios presented in the vignettes, as opposed to direct questions, may help to desensitise the issues⁽³⁷⁾. Vignettes are also able to control for contextual variations between vignette characters^(38, 39), thereby allowing all participants to respond to similar stimuli. Web-based vignettes are more cost effective than observational studies, and they facilitate the collection of a large amount of data in a relatively short time⁽⁴⁰⁻⁴²⁾. Vignettes may also help to ease participants' distrust of research

and minimise any potential harm from their participation⁽⁴³⁾. Additionally, vignettes are believed to reduce social desirability bias in responses through distancing participants' real lives by using hypothetical scenarios^(43, 44).

Video vignettes were preferred over paper-based vignettes in this study, as various clinical symptoms and psychosocial variables can be presented more realistically in video vignettes, which may ignite respondents' emotions, memories, attitudes and biases, and influence their responses⁽⁴⁵⁾.

3.3.4 Ethics

The Curtin University Human Research Ethics Committee approved the study (Approval No. PH-02-12), and informed consent was obtained from all participants prior to participation. Each participant was given a unique code to preserve confidentiality in electronic computer files, reports and publications associated with this research. The master list of names and codes was held in a locked facility at Curtin University. Research records are held accordingly to the regulation of the WA State Records Office.

3.3.5 Materials and procedure

3.3.5.1 Development of video vignettes

The videos were developed using the method described by Hawley et al.⁽⁴⁵⁾, which involved using professional actors and recording in a professional studio. Each vignette ranged between 20 and 30 seconds in length. The vignettes portrayed men (older or younger) experiencing one or more symptoms (rectal bleeding, diarrhoea and unintentional weight loss) for three days or three weeks and contemplating what to do about the symptoms.

Twenty-eight video vignettes (hypothetical scenarios) were developed. The content of the vignettes was informed by the National Institute of Health and Care Excellence (NICE) guidelines⁽²⁷⁾ for symptoms indicating high risk for CRC, and by clinical- and population-based studies^(46, 47-51). These studies showed that CRC symptoms are non-specific, and patients may ignore these symptoms rather than seek medical advice. Although lower bowel symptoms such as rectal bleeding, change in bowel habit, and unexplained weight loss (used in the vignettes) are common in the general population, they may also indicate advanced chronic bowel pathology^(7, 52-54). Abdominal pain, which is another common symptom in patients with CRC, was excluded from the vignettes because most people seek timely medical advice for this symptom^(50, 55-57). In addition, it has a lower diagnostic value for CRC^(58, 59).

CRC is assumed to be primarily a disease of the elderly, yet the incidence rate is higher in individuals aged over 50 years. Furthermore, recent evidence from an epidemiological study⁽⁶⁰⁾ from the US reported 180 people (11.2% of the total number of individuals affected by CRC) who underwent surgery for CRC between 1996 and 2012 were under 50 years of age (mean age 41.4 years \pm 6.2), and 94% of these individuals were symptomatic. The study concluded that as CRC was common in younger population with no family history therefore lower bowel symptoms in younger people warranted timely medical consultation to avoid late-stage presentation of CRC among these individuals. However, the risk of CRC in younger individuals (\leq 50 years) may increase if they have a family history of CRC. The population lifetime risk of CRC in a 50 year old may increase from 1.8% to 3.4% and 6.9% with one and two or more affected relatives respectively⁽⁶¹⁾. Therefore, age was used as one of the clinical variables for the vignettes, and vignettes were created using both older and younger men. Each scenario was presented as a short story and styled in the manner shown in the examples in Appendix 3.2.

3.3.6 Rationale for the use of clinical symptoms

Clinical symptoms used in the vignettes were selected based on their prevalence and risk of CRC. A brief description of the risk of pathology associated with lower bowel symptoms has been provided in Chapter 1 (Section 1.1.2) of this thesis.

3.3.6.1 Rectal bleeding

Rectal bleeding is a common lower bowel symptom and may be observed in conditions such as haemorrhoids or anal fissures; nevertheless, almost one-quarter of patients with rectal bleeding may also have a serious gastrointestinal (GI) disease such as IBD, polyps or colon cancer^(62, 63). The lifetime prevalence of rectal bleeding in the general population may be up to 38% in Western countries^(5, 46, 64). It is also a classic and one of the earliest symptoms of CRC⁽⁷⁾. The incidence rate of CRC (rate per 10,000 patient years) in men experiencing rectal bleeding is reported to be 34.2 vs. 1.4 in general population (in the 40–49 years age group). Likewise, the incidence rate is reported to be 529.3 in men experiencing rectal bleeding vs. 34.2 in the general population (in the 80–89 years age group). The absolute risk of CRC also increases with age in those experiencing rectal bleeding as well as in general population⁽⁶⁵⁾.

Although nearly 40% of CRC patients may experience rectal bleeding in their pre-diagnostic period, the risk of cancer associated with rectal bleeding is relatively low. In their prospective 10 year study in primary care setting in UK, du Toit et al.⁽⁶⁶⁾ observed that one in 10 patients aged 45 or over with new onset rectal bleeding had colorectal neoplasia. Based on this finding the authors suggested bowel investigation for all individuals over 45 years of age

whether or not they had any other lower bowel symptom. A new onset rectal bleeding presented with a positive predictive value (probability of disease among individuals with a positive test result) of 5.7% (3.2% to 9.2%) for CRC and 4.9% (2.6% to 8.4%) for adenoma⁽⁶⁶⁾. In their systematic review of evidence about the association of the lower bowel symptoms with CRC, Adelstein et al.⁽⁹⁾ reported that the sensitivity of rectal bleeding to CRC is estimated to be 0.46, which means only nearly half of the patients diagnosed with CRC would present with rectal bleeding. However, since bleeding also occurred in about one-quarter of the patients without cancer (1-specificity 0.25), the likelihood of CRC in patients presenting with rectal bleeding is almost double, likelihood ratio (LR)+ being 1.9⁽⁹⁾. The LR+ implies how much we can increase the probability of the disease if the results from the diagnostic tests are positive or the clinical usefulness of the symptoms. For the purpose of ruling in the disease based on symptoms, the LR+ values must be greater than 10. Thus, rectal bleeding presents a low risk of CRC in the community; nevertheless for the positive FOBT, the LR+ is nearly 47 indicating a high risk of cancer⁽⁶⁷⁾. Adelstein's review also indicated that the likelihood of cancer in those who did not present with rectal bleeding was LR- =0.7. However, the risk of CRC associated with rectal bleeding was higher when the blood was mixed with stool (LR+ 2.1 95% CI: 1.5-2.8) or was dark red in colour (LR+ 3.1 95% CI: 1.6-6.0)⁽⁹⁾. On the other hand, the LR+ for other symptoms such as diarrhoea (0.9 95%CI 0.5-1.6), constipation (1.1 95% CI,0.8-1.5), change in bowel habit (1.4 95% CI 0.9-2.1), and abdominal pain (0.8 95% CI 0.6-1.1) was observed to be relatively low⁽⁹⁾. The risk of CRC also increases with age and is nearly 10 times higher in people aged 70–79 years compared with those aged 50–59 years⁽⁷⁾. The positive predictive value (PPV) of CRC for rectal bleeding increases with age and is nearly 10 times higher in men aged 80-89 years compared with 40-49 years (9.13 vs. 0.92)⁽⁶⁵⁾. In accordance with Bayes' Theorem⁽⁶⁶⁾, the PPV of rectal bleeding for CRC varies with the prevalence of cancer in the general population, as well as the rate of bleeding in the cancer and non-cancer populations⁽⁷⁾. It is estimated to be highest among referred patients (5–7%), followed by those in general practice (2–3%), and it is lowest in the general population (0.1%)^(7, 68–70).

3.3.6.2 *Change in bowel habit*

Change in bowel habit can be described as a change in the frequency of defecation, consistency of stool shape and difficulty in evacuation⁽⁷¹⁾. Change in bowel habit is a common symptom in the general population and is estimated to have a lifetime prevalence of up to 19%⁽⁴⁶⁾. Chaplin et al.⁽⁶⁾ reported a one-year prevalence of around 25% for constipation, 10% for diarrhoea and nearly 23% for urgency of defecation among the British population aged over 65 years. Thompson et al.⁽⁵⁾ found that more than 50% of the UK population with rectal

bleeding also experienced a concurrent change in bowel habit. This is noteworthy as rectal bleeding and change in bowel habit increase the risk of CRC.

A high proportion of colon cancer cases are associated with changes in bowel habit; however, the risk is much higher in patients referred to secondary care or hospital than those in the general population ⁽⁷²⁻⁷⁴⁾. In people with changes in bowel habit, the incidence of diarrhoea is nearly three times higher than constipation ⁽⁷²⁾. In their systematic review however, Adelstein et al. ⁽⁹⁾ reported the Positive Likelihood Ratio (LR+) value of 1.4(0.9-2.1) and Negative Likelihood Ratio (LR-) value of 0.9(0.7-1.1). Additionally, the predictive value of diarrhoea for CRC is higher than constipation. Hamilton et al. ⁽⁷³⁾ observed that the PPV of diarrhoea and constipation for CRC in individuals consulting a primary care doctor was 0.63 and 0.2 respectively in the 40-69 years age group and 1.7 and 1.3 in the 70 years and over age group. Although constipation is not considered a high-risk symptom for cancer ⁽⁷⁵⁾, it has been suggested to be an important criterion for hospital referral ⁽⁷³⁾. Persistent changes in bowel habit have been associated with low HRQoL ⁽⁷⁴⁾.

3.3.6.3 Unintentional weight loss

The prevalence of unintentional or unexplained weight loss may range between 1.3% and 8% of adults seeking healthcare, and up to 25% of these patients may not have any obvious medical cause ⁽⁷⁵⁾. Lankisch et al. ⁽⁷⁶⁾ observed that although non-malignant diseases more commonly caused weight loss, the major cause of weight loss in both malignant and non-malignant conditions was a GI disorder. A GI tract disorder accounts for weight loss in every third patient; making benign and malignant GI disorders the leading causes of unintentional weight loss ⁽⁷⁷⁻⁷⁹⁾.

The diagnostic value of weight loss for CRC is high ⁽⁵⁸⁾. Adelstein et al. ⁽⁹⁾ found that weight loss occurred in nearly 20% of patients with CRC [sensitivity 0.20 (0.12-0.31)], and also occurred in less than 10% of individuals without cancer (1-specificity 0.08). Based on their findings, the authors suggested that the likelihood of CRC was more nearly two and half times in people presenting with weight loss [LR+ = 2.49 (1.5-4.0)] compared with those without weight loss. A loss of 5% of body weight over 6-12 months is considered significant ⁽⁷¹⁾. Weight loss in the elderly is also associated with an increased risk of mortality over a 12-month period ⁽⁷⁵⁾.

3.3.7 Study outcomes

The primary outcome for Study 1 was whether participants would advise the men in the vignettes to seek help. The secondary outcomes were where they would recommend men to

seek help (GP vs. other health professionals such as community pharmacists) and how urgently they should seek help. The final outcome was what factors will determine whether the participants would agree with the expert panel (of five GPs) about whether the characters in the vignettes should be referred for help seeking from a GP.

3.3.8 Questionnaire

Each participant answered a series of demographic questions before proceeding to the vignettes. Based on the scenario played in the vignettes, the respondents were asked whether the man in the vignette should seek professional health advice, which health professional he should seek advice from and how urgently he should seek advice. They were then asked questions related to the clinical scenarios presented in the video vignettes, based on five themes of the HBM: severity of symptoms (two items), susceptibility to symptoms (one item), benefits of seeking advice (two items), barriers to seeking advice (one item) and confidence (one item). These questions were informed by a literature review of questionnaires previously used in studies with a direct application of the HBM-based questionnaire on CRC and lower bowel symptoms (see Figure 3.2) ^(25, 26, 80, 81). The questionnaire was tested for reliability and validity as outlined below. The complete questionnaire is presented in Appendix 3.1. The respondents were asked to assess their level of agreement with each of the statements relating to these themes on a five-point Likert scale ('strongly disagree' to 'strongly agree').

3.3.8.1 Scoring

A five-point Likert scale (1='strongly disagree', 2='disagree', 3='not sure', 4='agree', 5='strongly agree') was used to score the items. Negatively worded questions ('barriers') were reverse-scored prior to analysis so that a high score indicated support for seeking advice and a low score indicated a reluctance to do so. When a theme consisted of more than one question, the mean of the responses to those questions was used to represent that theme. The Likert scale responses were recoded into numeric responses (1-5).

3.3.9 Psychometric analysis of the questionnaire

3.3.9.1 Reliability

A small sample of 23 males was selected and invited to complete the questionnaire twice—two weeks apart. The reliability of each survey question (demographic questions and video vignette questions) was assessed using the kappa statistic, as all survey responses were of a

categorical nature. For the 10 vignette questions, kappa ranged from a minimum of 0.88 to a maximum of 0.98. These results indicate a highly reliable questionnaire.

The domains of 'severity' and 'benefits' in the HBM were based on two questions each. Cronbach's alpha was calculated for each of these domains to identify the internal consistency of their constituent questions. Cronbach's alpha for the severity and benefits questions was 0.93 and 0.91, respectively. This shows very high consistency for the pairs of questions used in each of these domains.

3.3.9.2 Construct validity

Factor analysis was conducted on the results from the vignettes to identify the approximate contribution of each of the HBM domains to the total variance in the data. For this analysis and calculation of Cronbach's alpha, only one vignette was selected (at random) from each participant to avoid internal correlations between responses from the same participant.

Factor analysis of the HBM responses (after converting the Likert scale responses to the numbers 1–5) indicated that a single factor was responsible for 74.1% of the variance in the data. This factor involved all five domains used in the questionnaire, with four of them (severity, susceptible, confidence and benefits) having approximately equal weight, and the weight of the barrier domain was approximately half (and in a negative direction compared to the others). The factor loadings for the dataset were found to be: 0.941 (severity), 0.936 (susceptible), 0.934 (confidence), 0.918 (benefits) and -0.480 (barriers). This analysis confirmed that all domains were relevant and important in explaining the variance in the dataset.

The coding for the barrier questions was reversed so that a high score indicated that the barrier was not important. A single HBM score was calculated for each of the participants' vignette responses based on the factor loadings (a weighted sum of the five responses). The purpose of the factor analysis was to obtain a single summary score from the linear combination of the HBM questions that could be used in the subsequent regression analyses. To avoid the assumption of a linear relationship between the score and the odds of each outcome, the score for each person was categorised into one of four groups based on the quartiles of the score distribution (scores: 10, 15, 17). The grouped score variable was then introduced into the models as a categorical variable, with the highest quartile group (most likely to seek advice) used as the reference.

3.3.10 Questionnaire administration

The survey was administered via web-based software (<https://www.qualtrics.com/>). Eight of the 28 vignettes originally created, were randomly assigned to each participant⁽⁸²⁾. The randomisation was facilitated by an algorithm embedded in the software such that all levels of each variable were likely to be present in the vignette sample with equal probability^(35, 83). The same algorithm also eliminated the risk of repetition of a vignette presented to a participant. The online survey was pilot-tested by five men for ease of access to the web link to the survey, the functionality of the videos, the estimated time of completion and the data recording.

As mentioned previously, an expert panel reviewed all 28 vignettes and identified those that warranted seeking medical advice rather than other health professionals. The participants' responses to the vignettes were compared with those of the expert panel.

3.3.11 Data analysis

A GEE was used to identify the relative importance of the HBM, the symptom profile portrayed in the vignette and the demographic profile of the participant to the decision to seek advice from a health professional.

Three different GEE models were developed with three dependent variables respectively:

1. Seek advice
2. Seek advice from GP
3. Seek advice urgently (within a week).

The GEE regression model was used because it took into account the correlation in the data resulting from the multiple responses made by each participant (eight vignettes per person)⁽⁸⁴⁾. The results of the GEE models were presented as odds ratios, 95% CIs and *p* values. A number of explanatory variables were initially included in the models, and then demographic variables were dropped—one at a time—until the variables remaining in the model were significantly associated with the outcome. Particular symptom combinations, as presented in the vignettes and the HBM score, were forcibly included in the model.

Lastly, a fourth GEE model was developed to determine whether the respondents would agree with the expert panel (comprising five GPs) about seeking help. Observations for this analysis included those in which the expert panel decided that the men portrayed in the

vignettes should seek medical advice for their symptoms. The dependent variable was that the respondent agreed with the panel. Statistical analyses were performed using statistical software programs SPSS version 20 and SAS version 9.2. A p value of ≤ 0.05 indicated a statistically significant association in all tests.

3.4 Results

In the final survey, 408 out of 800 participants recruited to the study met the inclusion criteria and completed the study (response rate 51%). Each participant completed the demographic questions, then a set of questions about each of the eight video vignettes. A total of 3264 ($408 \times 8 = 3264$) complete responses to the video vignettes were received however five responses were incomplete or missing. The demographic profile of the study participants (see Table 3.2) was reasonably representative of the WA population in terms of age, marital status, country of birth, highest level of education and occupation ⁽²⁸⁾.

Table 3.2: Demographic profile of the study participants (n=408)

Variable	Frequency (%)
Age (years)	
18–29	23 (5.6)
30–39	100 (24.5)
40–49	120 (29.4)
50–59	91 (22.3)
60–69	57 (14.0)
≥70	17 (4.2)
Place of birth	
Australia	263 (64.5)
Other countries	145 (35.5)
Time spent in Australia (years)	
≤5	24 (5.9)
6–10	17 (4.2)
>10	367 (89.9)
Education	
Year 10 or less	109 (26.8)
Year 12	99 (24.3)
Technical/trade	84 (20.6)
Tertiary/university	115 (28.3)
Employment status	
Unemployed	12 (2.9)
Student	12 (2.9)
Employed part time	46 (11.3)
Employed full-time	273 (66.9)
Retired/pensioner/on social security	57 (14.0)
Other	8 (2.0)
Annual income	
<\$20,000	33 (8.1)
\$20,000–50,000	228 (55.9)
\$51,000–100,000	93 (22.8)
>\$100,000	40 (9.8)
Prefer not to answer	14 (3.4)
Relationship status	
Married	236 (58.0)
De facto	68 (16.7)
Separated/divorced/widowed	42 (10.3)
Never married	61 (15.0)
Private health insurance	
No	228 (56.4)
Yes	176 (43.6)
Frequency of GP visit	
Never	33 (8.1)
Once a year or less	176 (43.1)
Several times a year	185 (45.3)
1–4 times a month	14 (3.4)

3.4.1 Results of the GEE models

The proportion of participants seeking advice from a GP for vignettes featuring older men with symptom duration of three weeks ranged between 42% and 78% across all vignettes. For vignettes featuring younger men with similar symptom duration ranged between 26% and 84% across all vignettes with different symptom combinations (see Appendix 3.3).

Additionally, a disagreement was observed between the participants and the expert panel with respect to referring the men in the vignettes to seek help. Nearly 50% of the participants did not agree with the expert panel with respect to seeking medical advice for rectal bleeding lasting for three weeks. These findings are discussed in the subsequent parts of this chapter (Section 3.4.1.4 *vignette agreement with expert panel*).

3.4.1.1 Outcome 1: Seeking help for symptoms

Of the 3259 completed vignette assessments, 2076 (63.7%) were recommended to seek advice. The odds of recommending the men in the vignettes to seek help were lower if the participants resided in regional or remote areas as opposed to metropolitan areas (OR: 0.44, 95% CI: 0.23–0.83, $p < 0.002$), or if their annual income was $\leq \$50,000$ (OR: 0.30, 95% CI: 0.18–0.5, $p < 0.0001$). The odds of seeking help were also directly related to the respondents' HBM score** and their own frequency of GP visits. Those who never visited a GP were 72% less likely to advise the men in the vignettes to seek help compared to those who visited their GP several times per year (OR: 0.28, 95% CI: 0.15–0.54, $p < 0.0001$). Those with a HBM score of ≥ 15 were nearly 1000 times more likely to advise help seeking than those with a HBM score of < 10 (OR: 0.001, 95% CI: 0.0003–0.002, $p < 0.0001$). With regards to clinical factors, the odds of help seeking increased with the increasing number and duration of the symptoms. Table 3.3 shows the results of fitting a GEE model to these data, and it gives the odds ratios for seeking advice with 95% CIs and p values.

Table 3.3: Relative odds of men from vignette being referred to seek help

Variables	n/N (%) a ¹	OR a ²	95% CI	p value a ³
Symptom duration				
Three days	896/1600 (56.0)	1 (ref)		
Three weeks	1180/1659 (71.1)	2.59	1.97–3.39	<0.0001
Symptoms				
Rectal bleeding	243/466 (52.2)	1 (ref)		
Weight loss	118/467 (25.3)	0.15	0.09–0.25	<0.0001
Rectal bleeding and diarrhoea	379/469 (80.8)	2.12	1.31–3.44	0.0022
Rectal bleeding, diarrhoea and weight loss	395/471 (83.9)	2.78	1.71–4.52	<0.0001

Key:

a¹ The ‘n/N’ column shows the number of vignette responses seeking advice out of the total number of vignette responses in that category of the independent variable.

a² Odds ratios, CIs and *p* values were obtained from a GEE model that takes into account the correlations between responses from the same participant. The analysis is based on 3259 records (all data). Odds ratios greater than one indicated a higher likelihood of seeking advice; whereas odds ratios of less than one indicated a lower likelihood of seeking advice.

a³ Only statistically significant ($p \leq 0.05$) results have been included in the table.

*** For the purpose of the factor analysis was to obtain a single summary score from the linear combination of the HBM questions that could be used in the subsequent regression analyses. To avoid the assumption of a linear relationship between the score and the odds of each outcome, the score for each person was categorised into one of four groups based on the quartiles of the score distribution (scores: 10, 15, and 17). The grouped score variable was then introduced into the models as a categorical variable, with the highest quartile group (most likely to seek advice) used as the reference.*

3.4.1.2 Outcome 2: Seeking advice from a GP

Of the 2076 vignette responses in which participants recommended seeking health advice, 1517 (73%) recommended seeking advice from a GP as opposed to other health professionals such as pharmacists or nurse practitioners. The odds of recommending help seeking from a GP were higher in respondents aged ≥ 50 years compared to those aged < 50 years (OR: 1.65, 95% CI: 1.07–2.54, $p=0.023$). The odds were also lower for respondents who completed year 12 compared to those who had received tertiary education (OR: 0.31, 95% CI: 0.20–0.5, $p<0.0001$). Participants who earned between \$20,000 and 50,000 annually were much less likely to recommend seeking advice than those who earned $> \$50,000$ (OR: 0.13, 95% CI: 0.07–0.22, $p<0.0001$).

Men who believed that visiting a GP was time-consuming were 61% less likely to recommend help seeking from a GP (OR: 0.39, 95% CI: 0.26–0.59, $p<0.0001$). Additionally, those who

had a HBM score of <10 were half as likely as those with a score of ≥ 15 to recommend help-seeking advice from a GP. With regards to the clinical factors presented in the vignettes, the odds of consulting a GP increased with the increase in the number and duration of the symptoms. For lone symptoms, the odds were higher for rectal bleeding than for weight loss and diarrhoea. Table 3.4 shows the results of the final GEE model for this outcome.

Table 3.4: Relative odds of men from vignette being referred to seek help from a GP

Variables	n/N (%) b ¹	OR b ²	95% CI	p value b ³
Symptom duration				
Three days	604/896 (67.4)	1 (ref)		
Three weeks	913/1180 (77.4)	3.09	2.35–4.05	<0.0001
Symptoms				
Rectal bleeding	218/243 (89.7)	1 (ref)		
Diarrhoea	144/310 (46.5)	0.13	0.08–0.21	<0.0001
Weight loss	107/118 (90.7)	0.46	0.22–0.95	0.0353
Rectal bleeding and diarrhoea	264/379 (69.7)	0.65	0.44–0.95	0.0262
Rectal bleeding and weight loss	276/303 (91.1)	1.65	1.06–2.58	0.0267
Diarrhoea and weight loss	186/328 (56.7)	0.27	0.18–0.40	<0.0001
Rectal bleeding, diarrhoea and weight loss	322/395 (81.5)	1.60	1.07–2.41	0.0235

Key:

b¹ The analysis is based on 2076 records (records where no referral was thought to be necessary were excluded from this analysis).

b² While an odds ratios greater than one indicated a higher likelihood of seeking advice from a GP, an odds ratio of less than one indicated a lower likelihood of seeking advice from a GP.

b³ Only statistically significant ($p \leq 0.05$) results have been provided in the table.

3.4.1.3 Outcome 3: Seeking advice urgently

Of the 2076 vignettes that recommended seeking health advice, nearly 91% recommended seeking advice urgently (within one week). The odds of seeking advice urgently were lower for respondents with an income of <\$50,000 (OR: 0.17, 95% CI: 0.09–0.30, $p < 0.0001$).

Those who believed that visiting a GP was time-consuming (OR: 0.57, 95% CI: 0.38–0.86, $p < 0.0071$) or expensive (OR: 0.58, 95% CI: 0.36–0.93, $p < 0.02$) were less likely to advise urgent help seeking. Similarly, men with a HBM score of ≤ 10 were less likely (OR: 0.17, 95% CI 0.11–0.27, $p < 0.0001$) to advise urgent help seeking. Table 3.5 shows the results of the final GEE model for this outcome.

Table 3.5: Factors associated with the response to seek advice (from any health professional) urgently

Variables	n/N (%) c ¹	OR c ²	95% CI	p value c ³
Symptoms				
Rectal bleeding	219/243 (90.1)	1 (ref)		
Weight loss	101/118 (85.6)	0.38	0.18–0.79	0.0093
Rectal bleeding, diarrhoea and weight loss	371/395 (93.9)	1.68	1.05–2.67	0.0293

Key:

c¹ The analysis is based on 2076 records (records where no referral was thought to be necessary were excluded from this analysis).

c² An odds ratio of greater than one indicated a higher likelihood of seeking advice from a GP urgently, whereas an odds ratio of less than one indicated a lower likelihood of seeking advice from a GP.

c³ Only statistically significant ($p \leq 0.05$) results have been provided in the table.

3.4.1.4 Vignette agreement with the expert panel

Vignettes that were appropriately identified as warranting medical attention were defined as the participants' referral that matched the opinion of the expert panel. Only vignettes that were considered by the expert panel to require referral to a GP were included in this analysis.

Respondents aged ≥ 50 years were nearly twice as likely to agree with the expert panel in terms of advising the men in the vignettes to seek advice from a GP compared with those aged < 50 years (OR: 1.88, 95% CI: 1.23–2.87, $p < 0.003$). Respondents who lived in regional or remote areas as opposed to metropolitan areas (OR: 0.43, 95% CI: 0.26–0.72, $p < 0.001$), and those who had studied up to Year 10, as opposed to those who had received tertiary education (OR: 0.43, 95% CI: 0.25–0.75, $p < 0.002$). Participants with higher incomes were also more likely to agree with the expert panel. Participants who visited their GP at least once per month were nearly 16 times more likely to agree than those who never visited their GP (OR: 15.9, 95% CI: 2.71–93.81, $p < 0.002$), and those who believed that visiting a GP was time-consuming were 60% less likely to agree (OR: 0.4, 95% CI: 0.26–0.60, $p < 0.0001$).

Respondents who had a lower HBM score, visited their GP less frequently or believed that visiting a GP was time-consuming had lower odds of agreeing with the experts. With regards to clinical symptoms, the odds of agreement were higher for rectal bleeding as opposed to other symptoms, and they were higher when all three symptoms occurred concurrently or lasted for three weeks. The results of the final GEE model for this outcome are shown in Table 3.6.

Table 3.6: Relative odds of the participants agreeing with expert panel on the need for help seeking from GP

Variables	n/N (%) d ¹	OR d ²	95% CI	p value d ³
Symptom duration				
Three days	72/218 (33.0)	1 (ref)		
Three weeks	808/1425 (56.7)	8.22	4.62–14.62	<0.0001
Symptoms				
Rectal bleeding	119/236 (50.4)	1 (ref)		
Diarrhoea	119/344 (34.6)	0.26	0.16–0.41	<0.0001
Weight loss	31/118 (26.7)	0.14	0.07–0.29	<0.0001
Rectal bleeding and weight loss	159/239 (66.5)	1.92	1.23–3.00	0.0039
Diarrhoea and weight loss	122/230 (53.0)	0.50	0.33–0.76	0.0011
Rectal bleeding, diarrhoea and weight loss	256/356 (71.9)	4.37	2.66–7.19	<0.0001

Key:

d¹ The analysis is based on 1643 records (videos where the experts considered that referral to a GP was not necessary are excluded from this analysis).

d² An odds ratio of greater than one indicated a higher likelihood of seeking advice from a GP.

d³ Only statistically significant ($p \leq 0.05$) results have been provided in the table.

3.5 Discussion

3.5.1 Principal findings and comparison with previous work

In Study 1, a high overall HBM score was strongly associated with higher odds of recommending help seeking, thus highlighting the role of preventive health beliefs in regards to seeking medical advice for lower bowel symptoms. The findings in this study were consistent with some of the past studies that used the HBM as a theoretical framework^(25, 26, 85). The role of health beliefs such as beliefs about the severity of symptoms and about the confidence in the recommended health action in response to the symptoms observed in this study were also supported by Esteva et al.⁽⁸⁶⁾ in their research on the reasons for delay in help seeking.

The odds of referring the men in the vignettes for seeking health advice were also influenced by how often the respondents visited their own GP. For instance, those who visited their GP less frequently had lower odds of referring the vignettes for help seeking from a GP. Additionally, the odds of recommending help seeking from a GP or seeking advice urgently

(within a week) was lower for respondents who felt that visiting a GP was time-consuming or was expensive. As expected, respondents' socio-economic status also played a role in vignette referral. Men with lower household incomes (< AUD 50,000 vs. > AUD 50,000) and those with lower educational qualifications (educated up to or less than high school vs. tertiary educated) also had lower odds of recommending seeking medical advice. These findings are supported by past studies where socio-economic status has been independently shown to play an unfavourable role in men's help-seeking behaviour, suggesting that healthcare costs could be an important factor in determining the use of healthcare services for patients requiring medical attention⁽⁸⁷⁾. In a previous Australian study⁽¹³⁾, participants with lower levels of education were less likely to relate symptoms such as rectal bleeding, change in bowel habit and abdominal pain with CRC compared to those with tertiary level education. In the same study, it was also reported that participants who perceived lower susceptibility to cancer or who identified barriers to screening such as cost or the lack of confidence in the investigation were less likely to agree with preventive health check-ups⁽¹³⁾. This is supported by the current study, where participants with a lower HBM score (a cumulative score for the five domains of the HBM) were less likely to recommend referral of the men in the vignettes for medical advice. Thus the findings in this study corroborate with the HBM. In the current study, older individuals (participants ≥ 50 years) had higher odds of referring the vignettes for help seeking from a GP compared to younger individuals (participants ≤ 50 years). Whether this has any association with the perception of severity of the symptoms or susceptibility to cancer needs to be investigated. However, the finding contradicts the results of a study in a rural Queensland community, which reported younger individuals to be more likely to perceive higher susceptibility to CRC than older individuals⁽¹³⁾. Future studies that involve testing individuals' knowledge of the symptoms of CRC and its association in an age-stratified population may help in understanding the phenomenon. Among other demographic factors, respondents who resided in regional or remote areas were less likely to advise help seeking compared to those who lived in urban or metropolitan areas. These results are supported by a previous study conducted in a rural Queensland community, which found that although rectal bleeding was recognised as a symptom of CRC by most participants, very few could identify non-specific symptoms such as change in bowel habit, abdominal pain and unintentional weight loss to be associated with cancer⁽¹³⁾. Studies have also reported other factors such as availability, access to and cost of health services is important in determining healthcare utilisation⁽⁸⁸⁾. These factors are relevant for Australian men living in regional and remote areas, particularly those with limited access to health services for a variety of reasons which may include but are not limited to geographic isolation, poor transport links and shortage of healthcare providers⁽⁸⁹⁾.

Previous studies have shown that increased awareness of symptoms and the risk of disease by mass media or through lay support networks are known to trigger help seeking, while a lack of awareness of symptoms or treatments acts as a barrier to help seeking⁽⁹⁰⁾. The differential knowledge of symptoms and risk of CRC among men residing in rural versus metropolitan areas and its implication in help-seeking remains to be explored. Additionally, the reasons for the differences in the referral patterns of younger and older men in metropolitan areas compared to those in rural and remote areas needs to be investigated in future research. Although the odds of advising to urgent medical attention were positively related with the number of symptoms, the duration of symptoms (3 weeks vs. 3 days) had no statistically significant effect on the urgency of seeking health advice in this study.

Recommendations from the clinical practice guidelines in Australia and the UK^(91, 27) suggest for the urgent referral of at-risk patients (aged ≥ 60 years and with symptom duration of six weeks or more) to a hospital/secondary care services; however these guidelines do not specify a timeframe for seeking timely medical attention by individuals themselves. Although there is no correlation between the duration of symptoms and the stage of cancer at the time of diagnosis, late-stage presentation leads to a poorer five-year survival and mortality rate⁽²⁾.

One component of this study was to compare the participants' responses with the expert panel's recommendation about which characters in the vignettes should be referred to the GP. A disagreement was observed between the respondents and the expert panel with respect to seeking medical advice. Nearly 50% of the respondents did not agree with the expert panel in regards to referring vignettes portraying men with for rectal bleeding of 3 weeks duration. This finding is in line with previous studies reporting a low rate of help seeking for rectal bleeding^(6, 10, 46, 86, 89). Likewise, differences were observed between participants' and the expert panel's recommendations for other lower bowel symptoms described in the vignettes. Nearly one-third of respondents disagreed with the expert panel in regards to referring men in the vignettes for help seeking for unintentional weight loss or for change in bowel habit occurring concurrently with rectal bleeding and lasting for three weeks. This is a cause for concern, as persistent rectal bleeding (particularly in the absence of peri-anal symptoms) may be indicative of significant bowel pathology and warrants medical attention^(27, 92). Nearly a quarter of respondents disagreed with the expert panel regarding referring vignettes in which the men had all three symptoms—rectal bleeding, diarrhoea and weight loss occurring concurrently and lasting for three weeks. The age of the men in the vignettes had no effect on the level of agreement, as the respondents had similar advice for both younger and older men. This is again a cause for concern, as these symptoms are known to be associated with an increase of the risk of bowel cancer, particularly in the elderly^(9, 93, 94).

A number of respondents suggested seeking health advice for the symptoms and symptom combinations presented in the vignettes (rectal bleeding, diarrhoea and unintentional weight loss) from health professionals other than a GP, such as pharmacists and nurse practitioners. This suggests that other health professionals—especially community pharmacists—could play a vital role in educating men seeking advice about the risks of CRC based on their symptoms and subsequently advise them to seek medical advice from their GP ⁽⁹⁵⁾. Further discussion on the re-orientation of health services is provided in Chapter 7 in this thesis.

3.5.2 Strengths and limitations

The strengths of this study include a large and a fairly representative sample of WA population, hence impacting its external validity. The use of video vignettes to collect the data reduces possibility the participants' social desirability bias in regards to responding on symptoms that may be embarrassing.

This method of data collection also reduces the possibility of information-recall bias in the study as the participants as discussed in the earlier sections of this chapter. Past studies ^(3, 10, 96, 64, 97) have explored help-seeking behaviour in people who had previously experienced lower bowel symptoms, such as rectal bleeding and change in bowel habit. In a recent study, Courtney et al. highlighted factors associated with early medical advice-seeking behaviour for the potential symptoms of CRC ⁽⁸⁾. However, the time interval since exposure to symptoms is known to affect the recall of exposure ⁽¹⁰⁾.

One limitation of this study was that the participants were not tested for their knowledge of lower bowel symptoms in regards to CRC. Therefore, it would be difficult to suggest that men's lack of knowledge about the symptoms impacted on their referral of men in the vignettes for help seeking. It is also hard to hypothesise whether a public health campaign aimed at improving men's knowledge about the symptoms would lead to men offering better advice to other men. Thus it may be useful in future studies to explore men's knowledge of the potential risks associated with the symptoms presented in the vignettes and how it relates to help seeking. The cross-sectional nature of the study provides information about various predictors of referral for medical consultation; however the results of regression do not imply causality. In the current study, participants were not matched with the vignette characters for their demographic characteristics such as age and socio-economic status. This may also limit the study's external validity. Another limitation is that the participation in the study was limited to men who had access to the internet and a computer device such as desktop, laptop or tablet computer. It would be interesting to study whether men with no access to internet would respond differently to the vignettes. Lastly, Study 1 did not develop individual models

for different age groups for the purpose of risk stratification of CRC. Future studies could undertake models for individuals in lower risk groups such as those under 50 years of age.

3.6 Conclusions and implications

The current study aimed to explore the predictors (demographic and clinical characteristics and personal health beliefs of men) that may impact on how men would advise other men in regards to seeking health advice for lower bowel symptoms. Video vignettes were used to collect information from men in the general population in a cross-sectional survey. The findings suggested that a considerable proportion of men would not advise other men, even if they were experiencing multiple lower bowel symptoms, to seek help from a GP. Some factors associated with the low rate of referring vignettes for help seeking identified in this study were respondents' lower socio-economic status, living in regional or remote areas compared to metropolitan areas, and the time associated with visiting a GP. The HBM was an applicable model to study men's help-seeking behaviour in this study, and the HBM score, which was used as a measurement of men's health beliefs regarding the lower bowel symptoms, was directly related to the odds of recommending seeking help.

Knowledge of these predictors of referral to GP by men identified in this study may be considered in developing interventions aimed at encouraging timely medical-advice-seeking for lower bowel symptoms and facilitating early diagnosis among men. However, the associations identified in the study do not imply causality and need to be further confirmed in a longitudinal study. Given that, men <50 years of age were less likely to recommend seeking health advice, such men should be central to any intervention aimed at timely help seeking for lower bowel symptoms.

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**Chapter 4: Exploring the Barriers to Help Seeking Among Men
Who Do Not Seek Medical Advice for Their Lower Bowel
Symptoms: A Qualitative Study (Study 2)**

Publication

This study has been published in the *American Journal of Health Behaviour* as shown below.

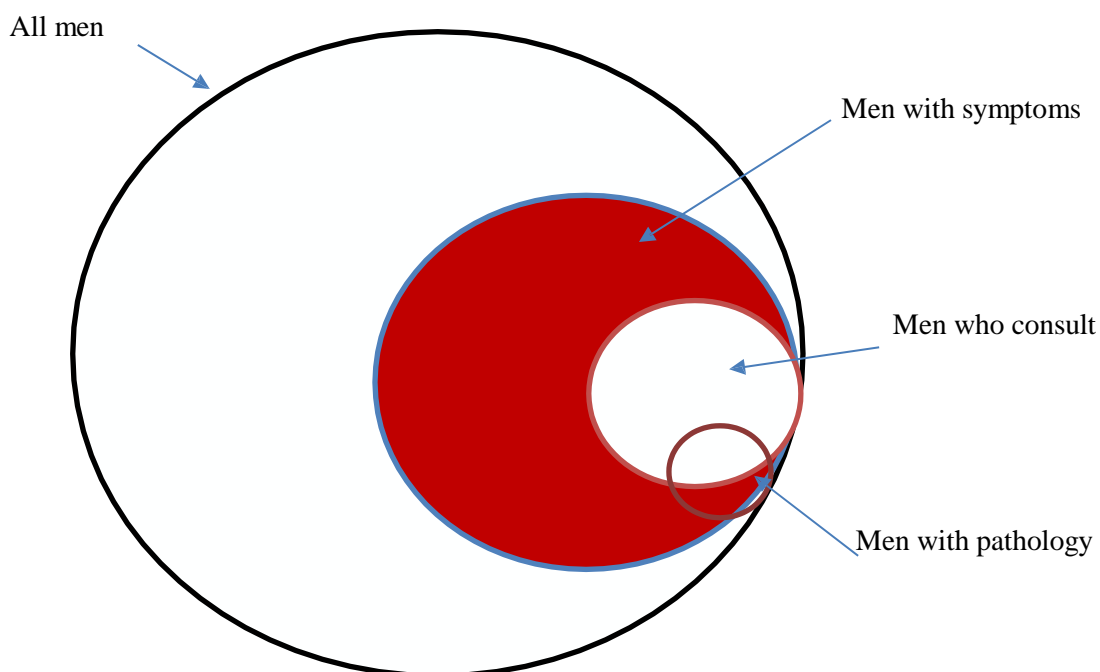
Citation

Oberoi DV, Jiwa M, McManus A, Hodder R. Men's help seeking behaviour with regards to lower bowel symptoms. *American Journal of Health Behaviour*. 2015; 39(2): 212-221. DOI: <http://dx.doi.org/10.5993/AJHB.39.2.8>

4.1 Summary

Study 2 forms the next step of this research project. It was the first of the three qualitative studies, and it aimed to explore the help-seeking behaviour (in regards to lower bowel symptoms) of men who did not seek medical advice for their symptoms. Figure 4.1 highlights the second of the four studies conducted as part of this thesis.

Figure 4.1: Schema of the thesis—Study 2 (highlighted)



Objective: Study 2 in this thesis aimed to explore the reasons as to why some men who experience lower bowel symptoms do not seek medical advice.

Methods: Semi-structured interviews were conducted with 13 male participants who were recruited via purposive sampling. Andersen’s Model was used as a theoretical framework for data collection and analysis. The interviews were taped, transcribed and analysed thematically.

Results: Failure to interpret the severity of the symptom was a common barrier to help seeking for a number of participants. Some participants did not seek medical advice because their symptoms were intermittent and were resolved with changes in diet and lifestyle or with OTC medications. Other barriers included the cost associated with consulting a GP, lack of confidence in medical consultation and fear of cancer diagnosis.

Conclusions: There is a need for health education and awareness campaigns aimed at men to educate men about the risk associated with persistent symptoms and increase their motivation to seek timely help. The experiences of men highlighted in the study should be compared with those who have been diagnosed with benign or malignant bowel conditions as this may provide an improved understanding of the factors associated with help seeking at different stages of the disease trajectory.

4.2 Background and objective

Lower bowel symptoms are common. They may affect the HRQoL and predispose an individual to the risk of CRC. To improve the HRQoL and facilitate the timely diagnosis of bowel pathology there is a need to explore the barriers to help seeking. Study 2 aimed to explore the barriers to help seeking among men who experienced lower bowel symptoms but did not seek medical advice.

4.3 Methods

4.3.1 Theoretical framework

Andersen's Model of Patient Delay⁽¹⁾ outlined various stages of delay in help seeking between symptom onset through to diagnosis and treatment. According to the model, the first major step after symptom onset is the appraisal of illness, which is mainly based on patients' knowledge of their symptoms. The time elapsed between symptom onset and their interpretation constitutes the first stage of delay in Andersen's Model and is known as *appraisal delay*. It is usually the longest stage of delay. After inferring the illness, the individuals may decide to seek medical attention, or take other steps such as to buy OTC drugs or do nothing about the symptoms and let the symptoms take their own course. The time elapsed before the patient decides to seek medical advice is an *illness delay*. The next step in the pathway is to act upon the decision to seek medical advice by arranging an appointment with a doctor. *Behavioural delay* is the time elapsed until the patient makes an appointment with the doctor, and the next stage in the model—*scheduling delay*—constitutes any delay between making an appointment with the doctor and actually visiting the doctor. The last stage in the model refers to any systemic delay in diagnosis, referral or treatment, which is collectively referred to as *treatment delay*. The first four stages of delay in this model are collectively referred to as patient delay—that is, delay in symptom interpretation (appraisal delay), delay in deciding to seek medical advice (illness delay), delay in arranging an appointment (behavioural delay) and delay in visiting a GP (scheduling delay). Of all stages, Andersen et al.⁽¹⁾ found that the stage of symptom interpretation, or appraisal delay,

constituted the major part of the delay in seeking medical attention. Study 2 in this thesis focused only on patient-related delay, as participants had not sought medical advice for their lower bowel symptoms before participating in this study.

4.3.2 Study design and sample

Semi-structured interviews were conducted with a purposive sample of 13 men in WA who were experiencing lower bowel symptoms such as rectal bleeding or change in bowel habit. Only men aged 18 years or older, who had experienced the symptoms for at least 3–4 weeks in a row in the past, and who had never presented to primary care or GP or never sought medical advice for these symptoms were eligible to participate in the study. The participants were recruited through a number of channels such as media advertisements via a local (Curtin) radio station and through media flyers. People who were willing to participate in the study in response to the advertisement contacted the researcher and were assessed for their eligibility to participate. Purposive sampling was used to ensure a diverse sample of men in WA with regards to age, nature of symptoms, educational and occupational status (see Table 4.1). The researcher (DO, PhD Student) provided potential participants with detailed information about the study, and informed consent was obtained. Ethics clearance was obtained from the Curtin University Human Research Ethics Committee (approval no: PH-02-12).

Table 4.1: Demographic characteristics of participants and symptoms experienced

Sl. No		Frequency
1	Relationship status	
	Married	8
	De facto	1
	Single (never married)	4
2	Private health cover	
	Yes	8
	No	5
3	Occupational status	
	Retired	2
	Currently working	9
	Tradesman (electrician, gardener)	2
	Professional (lecturer, researcher, school teacher, IT) professional	6
	Community support worker	1
	Unemployed	2
4	Educational status	
	Tertiary educated (university/TAFE/certificate courses)	6
	Up to Year 12	3
	Less than Year 12	4
5	Symptoms	
	Rectal bleeding	10
	Bloating	1
	Abdominal pain	4
	Constipation	2
	Diarrhoea	5
	Alternating diarrhoea and constipation	3

4.3.3 Interviews

The interviews were conducted via telephone, and notes were taken to supplement the interview transcripts. The interviews were audiotaped and transcribed verbatim for analysis. Data collection and analysis ran simultaneously, and the cumulative data were analysed after each interview. Sampling continued until no new information was obtained from the subsequent participants and ceased once data saturation was achieved and no new themes about the reasons for not seeking medical advice emerged. The interview questions were based on the first four domains of Andersen's Model: appraisal delay, illness delay,

behavioural delay and scheduling delay. As the participants in the current study had not sought medical advice at any stage of their symptoms, no questions based on treatment delay were asked. The interview schedule was based on the literature review, and the questions were developed based on the interview guide used by de Nooijer et al. ⁽²⁾ (see Table 4.2). The questions were developed by the principal investigator (DO, PhD Student) and were validated by an expert panel (n=3) comprising qualitative research experts and clinicians. Questions that were considered sensitive or closed-ended were re-structured or eliminated. The questions were pilot-tested on three participants with similar characteristics to the study population but who were excluded from the final sample, and their feedback was sought on the wording and language of the questions. The feedback was used to further refine the questions ⁽³⁾.

The principal investigator (DO, PhD Student) conducted the interviews. The participants were initially asked to narrate their experience of their lower bowel symptoms from the time they first noticed the symptoms. Thereafter, they were asked specific questions listed in the interview schedule. The participants were first asked questions related to the first stage of delay in Andersen's Model (i.e., appraisal delay), followed by a set of questions related to the other stages of delay in the same order as Andersen's Model (i.e., illness delay, behavioural delay, scheduling delay). To retain the semi-structured nature of the interview schedule, minor variations were made in the sequence of questions asked within each stage of the model based upon the participants' responses to the preceding questions ⁽³⁾. This allowed the researcher to collect the same general areas of information while allowing for flexibility and a degree of freedom in collecting information from the participants ⁽³⁾. A few questions in the interview schedule were probing questions that were developed to enable the researcher to gather specific information from the participants based on their responses to the pre-structured questions. Slight variations were made to the order of questions during the interviews when the researcher felt the need to provide prompts to the participants.

Each interview lasted 30–40 minutes. In addition to audiotaping the interviews, the researcher prepared field notes from participants' responses during the interview. To establish the credibility of the noted information, and to ensure that the interviewer had correctly understood and interpreted the information given by the participants, the information obtained during each interview was subjected to member checking or validation ⁽⁴⁾. To achieve this, the noted information was narrated to, and crosschecked with, the study participants at the time of the interview.

Table 4.2: Interview schedule

Stage of Andersen's Model	Important questions
Appraisal delay	<ol style="list-style-type: none"> 1. Could you narrate your experience with bowel symptoms? 2. What symptoms have you had and for how long? 3. How did you feel about the symptoms when they had just started? What did you think the symptoms were due to? OR 4. What did you think the symptom meant? Or what was your perception about the symptoms? 5. At any stage, did the symptoms cause any concern? OR 6. Did you do anything about those symptoms (seek help or treatment)? 7. Did you speak with anyone about your symptoms? Whom did you speak to? (Prompt: If yes, was it useful talking to them at that stage? If no, was there any specific reason for not discussing with anyone about your symptoms?)
Illness delay	<ol style="list-style-type: none"> 8. Did you go to the pharmacy for some medication? OR 9. What led you to go to the pharmacy? Did someone encourage you to go to the pharmacist?
Behavioural delay	<ol style="list-style-type: none"> 10. How long did you wait before you sought any help for those symptoms? (E.g., in visiting the pharmacy). If so, why did you wait for that long? OR 11. Do you think you could have sought help earlier than you did? If so, what made you wait for that long? 12. Were you embarrassed to speak about these symptoms to anyone? 13. Are you aware of any association of these symptoms with any underlying bowel disease?
Scheduling delay	<ol style="list-style-type: none"> 14. Whom did you seek help from about your symptoms? (Prompts: What did you tell them about the symptoms? Were there any symptoms that you did not want to talk about?) 15. Did they offer you any treatment? 16. Do you think you will need to see your GP about these symptoms? (Prompt: At what stage do you feel that is likely to happen?)

4.3.4 Data analysis

The interview schedule and Andersen's Model were used as the framework for data analysis. The data were analysed using thematic analysis based on key concepts in the interview schedule. Once the data collection was complete, the interview transcripts were reviewed by the principal investigator (DO, PhD Student), and emerging themes and subthemes noted within the framework of Andersen's Model. The text from the transcripts was coded to identify the underlying tentative themes in regards to the original data and the audiotapes of the interviews. The emergent themes were discussed with other researchers (MJ, AM; Thesis Supervisors) who are qualitative research experts. The researchers critically evaluated the themes in light of the transcripts and audio-recordings in order to verify the validity of the

themes, and they were finalised only after a consensus was reached. Details about the steps involved in identification of the themes are provided in Section 6.3.4 of the thesis.

4.4 Results

Participants varied in age (mean age 45 years, age range 26–81 years) and duration of symptoms [mean duration of symptoms: 5.19 years (\pm 4.91)]. The commonly experienced symptoms were rectal bleeding, diarrhoea, constipation, alternating diarrhoea and constipation, bloating, and abdominal pain. None of the participants had ever sought medical advice for their symptoms. Table 4.1 presents the participants' characteristics and the time elapsed since the onset of symptoms.

4.5 Themes

4.5.1 Appraisal delay

4.5.1.1 Rationalisation of the symptoms

The data obtained via interviews illustrated that the interpretation of the lower bowel symptoms was an important factor in the appraisal of symptom severity. None of the participants linked the symptoms to any major bowel pathology. The attribution of symptoms to common causes other than bowel pathology was one of the main reasons for not seeking medical advice. The participants attributed their rectal bleeding to chronic conditions such as haemorrhoids (n=4), as well as other factors, such as wiping with toilet paper too hard and too often (n=2), and diet (n=4). Men who attributed their symptoms to diet believed that junk food or spicy food, rich creamy salads, binge drinking and not eating regularly caused the symptoms.

'My stomach gets upset quite easily as I also have this acid problem and my stools are a bit running ... aah ... I was a little bit worried but I wouldn't panic. I know it's normal when your diet's not great'. Male, 59 years, symptom duration one and half years.

Two participants attributed their diarrhoea to 'Bali belly' or frequent travel to Bali (a tropical island in Indonesia). Most men, who attributed their symptoms to haemorrhoids, had read about the condition on internet or from discussions with other people. One participant believed that bleeding was not serious or did not warrant medical advice unless it was mixed with stool or was observed directly in the toilet bowl. Another participant mentioned that

unless the blood observed on the toilet paper was dark in colour, he would not associate the symptom with bowel pathology:

'I didn't think there was any cause, that's normal variation because it wasn't out of the blue. The bleeding ... umm my understanding is that if you have bowel problems, you have old blood, darker blood rather than the new blood turning red'. Male, 37 years, symptom duration two years.

A few participants (n=3) attributed their bleeding to their on-going mental and physical stress at work. One participant believed that his symptoms resulted from anal surgery in childhood (n=1). Surprisingly, one participant, who was an active marathon runner, attributed his symptoms to long workouts and training sessions at the gym. He also acknowledged that when the symptoms disappeared on cessation of training, his belief about the cause of the symptoms was further strengthened and validated:

'I think it (the symptoms) was related to my sports activity ... because it was very, very intense and when I kind of realised that it was related to the intense sport activity umm ... I assumed that it was not a risk for my health'. Male, 38 years, symptom duration six years.

One participant mentioned that he was a frequent visitor to Bali, and when he started experiencing occasional diarrhoea, both he and his wife decided not to visit a particular restaurant in Bali, which they suspected was the cause of their symptoms. The interviews showed that, in general, the lack of knowledge about the cause of symptoms and incorrect interpretations of symptoms were factors influencing the inference of illness and therefore consultation behaviour. The lack of awareness of being at risk also led men to not seek medical advice.

4.5.1.2 Symptom disclosure with significant others

Nearly half of the participants (n=6/13) had discussed their symptoms with a significant someone (wife n=4, father n=1, friend n=1). The reasons cited by other participants (n=7/13) for not discussing their symptoms were: embarrassment about the symptoms, non-persistent symptoms, symptoms not considered serious enough to warrant a disclosure, or because it was a personal issue. Two men mentioned that they had been advised by their wives to see a GP, but they did not follow this advice because their symptoms were non-persistent:

'I think the first time it happened was when I was at work. I went home and it sort of stopped by then and I spoke to my father ... and sort of ... yeah ... and he said it was symptomatic of

haemorrhoids. I just took a bit more care for wiping and things like that. And it seemed to go away'. Male, 33 years, symptom duration 13 years.

Some participants (n=3) were relieved of any anxiety about the symptoms when they were told by other people in their lay network that the symptoms resulted from common causes such as haemorrhoids. One participant was relieved after discussing his symptoms with a friend who was also experiencing similar symptoms and had visited a GP. He subsequently dropped the idea of seeking medical advice because he was assured that his symptoms were the outcome of his training:

'Because in particular I have this guy in my mind who was scared, he went to have a ... like a colonoscopy, because he was bit older than me, he was already 50, he was thinking like he may have [a] tumour, so he went to the doctor and he had conclusions that the symptoms were related to high sport activity, and secondly, he was eating lot of fruits and vegetables. But that's what he told me but it really made me feel comfortable that what was happening with me was due to training and training'. Male, 38 years, symptom duration six years.

Four participants were advised by their partners to see a GP for their symptoms; however, they did not consider their symptoms to be serious enough to warrant medical advice.

4.5.2 Illness delay

4.5.2.1 Self-management of symptoms

Although the participants did not consult a GP for their symptoms, most of them attempted to manage their symptoms through OTC medications (n=4) or changes in diet (n=5). One participant, who attributed his symptoms to heavy workouts at the gym, mentioned that reducing his workout level had helped relieve his symptoms. Another participant believed that his symptoms resulted from mental and physical stress, and that the symptoms improved when he changed his diet to fruit and vegetables and eliminated coffee from his daily routine. He also mentioned that he had had similar symptoms when he was younger because of exam stress in college. Most participants did not seek medical advice because their symptoms were inconsistent or intermittent (n=8). They believed that their symptoms did not warrant medical attention and hoped that they would resolve spontaneously.

4.5.3 Behavioural and scheduling delay

4.5.3.1 Fear of diagnosis and unpleasant investigation

Fear of cancer prevented help seeking in a minority of participants (n=2). The fear was related to various aspects of cancer, including thoughts about unpleasant treatment, poor prognosis and general anxiety associated with visiting a GP:

'Aah look, I guess there is always a level of anxiety umm when you have to go to the GP with such a thing. I know I am fairly young and the chances of developing cancer are very small at that age, you don't know what to expect. So I was a bit anxious, yeah...' Male, 37 years, symptom duration two years.

4.5.3.2 Cost of consulting a GP (time and money)

Another important reason for not seeking medical advice for symptoms was the participants' perception that consulting a GP was time-consuming (n=6). Finding time to visit a GP was low on their list of priorities because of other professional, family and social commitments. One participant mentioned that although he was receiving a lot of encouragement from his sister to see a GP for his symptoms, he did not have time to arrange the appointment or book the required tests. Further, two participants mentioned that they did not see their GP because of the associated monetary cost. A few participants expected that visiting a GP would help, but they were prevented from seeking medical advice for other reasons, such as a lack of time and the perception that the symptoms would resolve spontaneously:

'I mean I'm busy at work ... I have a family with two young girls. You know, maybe having to take some time off from work to make an appointment to go and see the doctor ... so you know it was never high enough on my priority to go and make a doctor's appointment about it'. Male, 43 years, symptom duration three years.

4.5.3.3 Participants' confidence in medical consultation

Another factor influencing participants' help-seeking behaviour was their lack of confidence in the consultation and the expected benefit of consulting a GP for lower bowel symptoms. Nearly half of the participants (n=8) did not expect their GP to help with their symptoms, assuming that a GP would either recommend dietary changes or refer them to a specialist. Some participants (n=3) mentioned that they had lost their confidence in medical consultations. One of them felt that GPs were of minimal help for issues related to the bowel, and that naturopathy was a better option. One participant mentioned that he was 'sick and tired' of getting a wrong diagnosis in the past for other medical issues and had therefore

given up the idea of ever visiting a GP in future unless he had a major accident or emergency. One participant did not seek help, as he speculated that a GP would simply advise him not to worry about the symptoms and wait until they resolved spontaneously:

'I just figured out that there is not much they can do other than recommend diet changes and I thought I could probably figure that out myself'. Male, 26 years, symptom duration three years.

4.6 Discussion and conclusions

Rationalisation of symptoms, perception that the symptoms were not severe enough to warrant a help seeking or the attribution of the symptoms to on-going mental or physical stress were the main themes that emerged from the interviews as barriers to seeking medical advice. An improvement in symptoms or health condition following the use of OTC medications or with changes in diet further reinforced their view about the low severity of symptoms. As discussed in the results, a few participants in Study 2 were too embarrassed to disclose their symptoms to others (family or friends). On the other hand, some participants, who discussed their symptoms with significant others, were reassured that they need not worry about the symptoms as the symptoms were not serious. The time and monetary costs associated with visiting a GP and lack of confidence whether the GP would be able to help with their symptoms were other barriers to help seeking.

In Study 2, only two participants associated their symptoms with potential cancer diagnosis. However, most participants attributed their symptoms to haemorrhoids (rectal bleeding), improper eating habits (change in bowel habit) or other non-medical causes, such as inappropriate diet, excess alcohol, or mental and physical stress. Participants' inability to associate their lower bowel symptoms with chronic bowel conditions and their attribution of the symptoms to causes unrelated to bowel pathology is consistent with the first stage of Andersen's Model, the *appraisal delay*. Nevertheless, it would be difficult to suggest that these participants lacked adequate knowledge about the association of symptoms with a variety of chronic bowel conditions and CRC, as the current study did not test participants' knowledge about the cause of symptoms. Such information can be confirmed in a longitudinal study. Knowledge about potential cancer symptoms is pertinent to correct interpretation of symptoms warranting medical advice whereas lack of such knowledge may encourage people to disregard the symptom severity, thus preventing them from seeking medical advice ^(5, 2). Thus, the assessment of men's knowledge about the risk posed by persistent lower bowel symptoms and its impact on timely help seeking would be an important area of study in future research. In their study on a Dutch population, de Nooijer et

al. ⁽⁶⁾ observed that patients who responded to possible cancer symptoms had sufficient knowledge of cancer to interpret their bodily changes correctly. Studies have shown that individuals with low-risk symptom profiles (such as those experiencing rectal bleeding with peri-anal symptoms, transient change in bowel habit, rectal bleeding with no persistent change in bowel habit or change in bowel habit in the absence of rectal bleeding) have a low diagnostic yield of CRC ⁽⁷⁾. The findings from Study 2, although concerning, are not surprising because it is well known that the prevalence of lower bowel symptoms in the general population is high and most people do not seek medical advice or delay to seek help. On the other hand, the barriers to help seeking identified in this study highlight important issues as to why even men with persistent and progressive symptoms refuse to visit a doctor. The persistent symptoms may lead to serious benign bowel pathology such as IBS and IBD and may significantly impair HRQoL ⁽⁸⁻¹⁰⁾ whereas, timely help seeking followed by the treatment of benign bowel conditions such as IBS is likely to improve HRQoL in these patients ⁽¹¹⁾.

The interviews in the current Study also identified that a few participants did not seek medical advice because they believed that their symptoms could be managed with OTC medications or with changes in diet. These findings relate to the second stage of delay outlined in Andersen's Model, *illness delay* in the pathway to seeking help. The symptomatic pharmacological management of diarrhoea and constipation with anti-spasmodic/anti-diarrhoeal and prokinetics/high-fibre supplements, respectively, in individuals with IBS is an important and a common treatment approach. Furthermore, low intake of dietary fibres, high caffeine consumption and high lactose intake contribute to IBS symptoms ⁽¹²⁾. Therefore, it is not very surprising to note that a few participants in Study 2 decided not to seek medical advice when their symptoms improved with OTC medications or with changes in dietary habits. However, this also offers an opportunity for the role to be played by other healthcare professionals for men experiencing lower bowel symptoms. As men are likely to visit a community pharmacy at some point during the course of their symptoms, community pharmacists play a vital role in not only in the management of bowel symptoms but also in profiling high-risk individuals. As the sole reliance on OTC medications or pharmacists' advice for their symptoms may not be enough for men, especially for those with persistent symptoms and family history of disease, individuals with persistent lower bowel symptoms and who are identified at risk of bowel pathology could be referred to a GP. Past studies have supported the use of questionnaires to as screening tools for high-risk individuals. The Jodi Lee Test (JLT) developed by Sriram et al. ⁽¹³⁾ is a self-administered questionnaire-based screening tool with high sensitivity for identifying patients with symptoms of serious bowel disease at community pharmacies and referring them to primary care.

Among the factors associated with behavioural delay, the findings from Study 2 suggested that a few participants considered help seeking from a GP to be time-consuming and some found it expensive. Other men found it embarrassing to discuss their symptoms with their GP. A fear of cancer diagnosis and a lack of confidence in GPs were other emergent themes with respect to patient delay. These findings are supported by previous research by de Nooijer et al. ⁽²⁾, wherein the patient did not expect the GP to be of significant help in relation to the last stage of patient delay in the pathway to diagnosis—scheduling delay.

The findings regarding patients' confidence in their doctor in regards to seeking help suggested that unsatisfactory or disappointing past medical experiences, or the assumption that a GP would not be able to offer any help other than recommending changes in diet or referring them to a specialist, were central to participants' decision not to seek medical advice. Such findings are supported by past studies. A study by Meyer et al. ⁽¹⁴⁾ showed that patients with established pathology were more likely to trust their GP compared to primary prevention patients. Thus, it is plausible that patients would be more concerned about their symptoms and more likely to seek timely medical advice after they were diagnosed with bowel pathology. Findings in Study 2 also suggest that for some men, barriers to seek help such as the lack of time to visit a GP, or fear of cancer diagnosis may outweigh the benefits associated with seeking advice. de Nooijer et al. ⁽²⁾ found that patients who believed that the benefits of consultation outweighed the barriers were more likely to consult their GP. Further, factors such as GPs' professional skills and clinical judgement and their knowledge of the patient may affect patients' confidence in their GP ^(16, 17). The current research did not investigate these factors as the basis of participants' repose in their GP; however, this may be investigated in future research. Additionally, in the current study, it is not clear whether or not the participants' suboptimal experiences with their GP in the past with regards to lower bowel symptoms acted as a barrier to help seeking. Thus, with limited information on this issue and since the information provided by the participants was not validated with their doctors, it is difficult to make any conclusions. The influence of patients' trust in their GP and the medical system on help seeking for lower bowel symptoms was beyond the scope of this thesis and may be studied by researchers in future.

Less than 50% of participants in the current study had disclosed their symptoms to a significant someone (family or friend). The reasons for not disclosing the symptoms were privacy related issues or the perception that the symptoms were not severe enough to warrant medical attention. Previous studies have shown that symptom disclosure to a significant someone acted as a facilitator to seek advice, thus highlighting the role of participants' lay network in encouraging them to seek timely medical advice for their symptoms ⁽²⁾. Further,

external factors such as reassurance from the lay network comprising of family and friends, about the symptoms acted as a barrier to seeking help. For instance, a friend who had previously sought advice for lower bowel symptoms and was not diagnosed with any bowel pathology acted as a reassuring factor for a participant in this study, thus he did not seek medical advice. Thus future studies should focus on the role of such people in facilitating timely help seeking among men. Interventions targeting men's help-seeking behaviour should also involve family members.

The findings of Study 2 provide insights into a more focused approach to facilitating timely help seeking among men for their lower bowel symptoms. These findings are relevant, particularly against a backdrop where medical-advice-seeking rates in the general population have remained low in the past two decades, despite several educational and health promotion campaigns ⁽¹⁸⁻²⁴⁾. There is also need to facilitate symptoms appraisal by improving men's awareness of the implications of longstanding or persistent lower bowel symptoms with respect to diminished HRQoL and the possibility of cancer diagnosis, especially in high-risk groups ⁽²⁵⁾. Public awareness campaigns have value as they inform about signs and symptoms and the benefits of seeking help in a timely manner. They may also help to alleviate fears about cancer diagnosis. The information offered in such campaigns should be balanced to encourage those at risk to seek medical advice ⁽⁷⁾. A probable increase in the proportion of individuals seeking consultation in primary care should be considered and strategies to cope with patient load implemented ⁽¹⁷⁾. As these symptoms are common for chronic bowel conditions and benign and malignant diseases, further research is required to gain insights into the factors facilitating help seeking in men with an established diagnosis of bowel pathology. This would be the objective of the following studies in this thesis.

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**Chapter 5: Barriers and Facilitators to Help Seeking Among Men
Diagnosed With Benign Colorectal Diseases: A Qualitative Study
(Study 3)**

Publication

This chapter was published in the *American Journal of Health Behavior* as shown below.

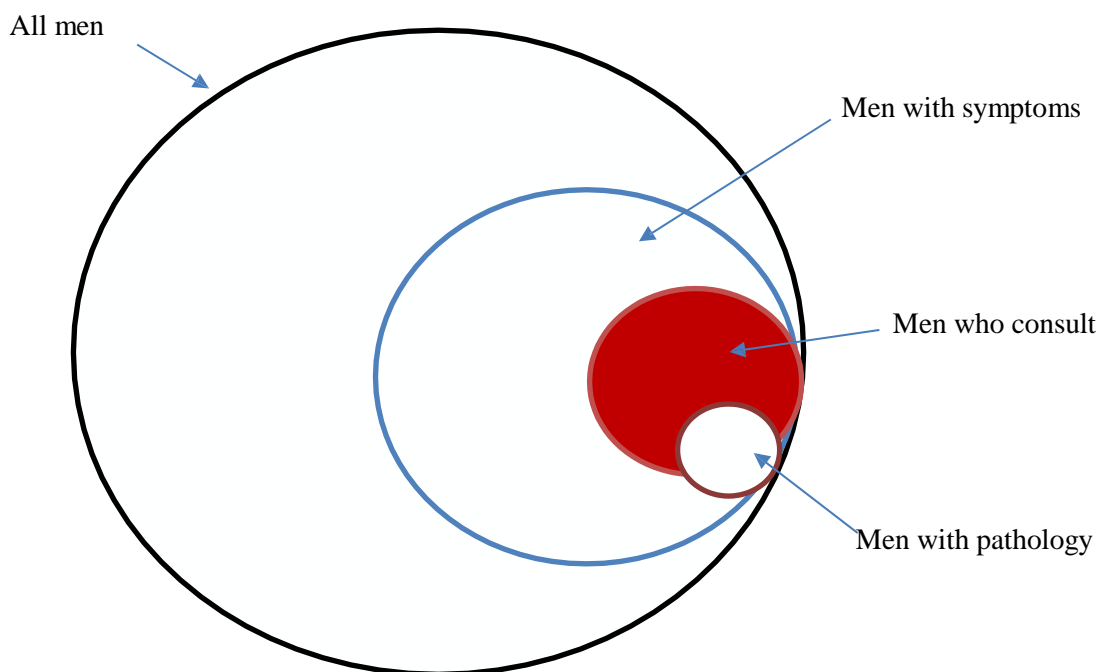
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5.1 Summary

Study 3 formed the next step of the trajectory. It aimed to explore the help-seeking behaviour of men (in regards to their lower bowel symptoms) diagnosed with benign colorectal diseases. Study 3 is the third of the four studies conducted as part of this thesis and is represented by a coloured circle in Figure 5.1.

Figure 5.1: Schema of the thesis—Study 3 (highlighted)



Background: Benign colorectal diseases present with similar features as those of CRC. Longstanding disease may affect quality of life and may increase the risk of CRC. The diagnosis of benign bowel conditions requires similar investigations as those for CRC.

Study Objective: The current qualitative study sought to explore the help-seeking pathway for lower bowel symptoms in men diagnosed with benign bowel diseases.

Methods: In-depth semi-structured interviews were conducted in a purposive sample of men (n=19) diagnosed with benign colorectal diseases following a colonoscopy. The interviews were audiotaped and transcribed verbatim. The data were analysed thematically. Andersen's Model was used as a theoretical framework for data collection and analysis.

Results: There was evidence of delayed presentation of lower bowel symptoms. The reasons for delay were categorised into the five stages of Andersen's Model. The greater proportion of delay in diagnosis was related to patient delay, whereas treatment delay played little role

in the pathway to diagnosis. The major factors in delayed diagnosis were attribution of symptoms to self-limiting conditions, misinterpretation of symptoms and failure to make time to visit a GP. Other factors were low expectation of help from a GP, fear of cancer diagnosis and embarrassment associated with the symptoms. The factors that facilitated help seeking were the exacerbation of symptoms, disclosure of symptoms to a confidant and encouragement to consult a GP by a female family member.

Conclusion: Improvements to the early diagnosis of bowel disease may be mediated by interventions to remove the embarrassment surrounding consulting for lower bowel symptoms, facilitate access to GPs for employed men and encourage the role of family members in promoting consultation.

5.2 Background

The process of establishing a diagnosis requires people to seek medical advice, followed by history taking by the GP, general medical examination, laboratory investigations and when deemed necessary, a colonoscopy⁽¹⁾. Nevertheless, factors such as bowel preparation prior to a colonoscopy, anxiety or anticipation of pain and the fear of cancer diagnosis are known to act as barriers to seeking medical advice for lower bowel symptoms⁽²⁾.

5.2.1 Effect of benign colorectal diseases

Benign colorectal conditions such as IBD and IBS are known to impair patients' HRQoL⁽³⁻⁵⁾. Previous studies have suggested that anxiety, depression and social isolation resulting from these diseases may affect social and emotional wellbeing, while bowel symptoms may affect physical wellbeing^(6,7). At times, the symptoms may be embarrassing and humiliating for patients and may have profound negative socio-economic effects such as loss of education and difficulty in gaining employment and/or insurance^(1,8,9). A recent Australian study on people with IBD (n=166) by Leong et al.⁽¹⁰⁾ found that nearly 20% of patients had a moderate work disability, which limited their capacity for full-time employment or study, while nearly 7% had a severe disability.

Longstanding benign colorectal diseases may also increase the risk of CRC. People with longstanding IBD have a two- to threefold higher risk of CRC compared with the general population, and the risk increases further with the extent of bowel inflammation^(11,12). The major risk factors for CRC in this group include younger age at diagnosis, extent and duration of the disease, and a family history of CRC⁽¹³⁾. In some cases, IBD may act as a precursor to CRC through the inflammation–dysplasia–cancer sequence; therefore, a surveillance colonoscopy is recommended for the detection of intraepithelial neoplasia in

people with longstanding IBD^(13, 14). The National Health and Medical Research Council's (Australia) Clinical Practice Guidelines⁽¹⁵⁾ suggested that the onset of symptoms, such as rectal bleeding and change in bowel habit (within the past 6–12 months), must raise suspicion of CRC, especially in high-risk groups (aged >40 years, with a family or personal history of CRC or adenoma or with a personal history of IBD). The guidelines also suggested that these symptoms must not be conveniently attributed to common chronic conditions such as haemorrhoids, as prompt medical attention for these symptoms facilitates the timely diagnosis of CRC in respective patients. Thus, seeking timely medical advice is critical for improved HRQoL and for the early diagnosis of cancer.

5.2.2 Failure to seek medical advice

A study by Sladden et al.⁽¹⁶⁾ on general practice patients in Australia found that 45% of patients with rectal bleeding who had consulted their GP had interpreted their symptom more seriously than those who had not consulted. A review of the literature showed that most of the studies on help-seeking behaviours for lower bowel symptoms focused on individuals in the general population^(17–21) or those diagnosed with CRC^(22–26), and there was limited information on the help-seeking behaviour of men diagnosed with other chronic colorectal diseases such as IBD and benign conditions such as polyps. In their study on people with IBS in Sweden, Ringstrom et al.⁽²⁷⁾ observed that those who had mild symptoms and those who could control their symptoms were less likely to consult a doctor, with a few sought alternative therapies or advice from their lay networks. In a recent study, Norton and Dibley⁽²⁸⁾ found that most people with IBD-associated faecal incontinence did not seek medical advice because of embarrassment or unawareness of the help available for their symptom; however, the authors did not study help-seeking behaviour for other lower bowel symptoms.

Early diagnosis and treatment could improve HRQoL of people with IBD⁽²⁹⁾ and may also contribute to cancer prevention. Past studies have highlighted several behavioural and demographic factors associated with lower rates of help seeking which have been discussed in Chapters 1 and 2 in this thesis.

5.3 Objective

Study 3 in this thesis aimed to explore the help-seeking behaviour of men from the onset of lower bowel symptoms to the diagnosis of benign colorectal diseases.

5.4 Methods

5.4.1 Theoretical framework

As with Study 2 (see Sections 4.3.1) Andersen's Model ⁽³⁰⁾ was used as the theoretical framework to guide the interview schedule and data analysis.

Study setting and sample

A sample of male participants (n=19) diagnosed with benign colorectal diseases following a diagnostic colonoscopy was included in Study 3. Purposive sampling was used to interview men from varied age groups experiencing different benign colorectal conditions. Participants had one of the six colorectal diseases: polyps (n=7), Crohn's disease (n=3), diverticulitis (n=3), internal haemorrhoids (n=3), IBS (n=2), volvulus (n=1). The sample was selected from outpatient clinics at a large tertiary care teaching hospital in WA over a five-month period (February 2013–July 2013). The sample characteristics are listed in Table 5.1. Participants with a past history of CRC were not included. The data were collected via face-to-face interviews with the participants. Data collection ceased once data saturation was achieved and no new information was obtained from the subsequent participants. The consulting doctor provided the participants with detailed information about the study, and the principal investigator (DO) contacted the potential participants. All relevant local research and ethics committees approved the study (approval numbers: Curtin University Human Research Ethics Committee PH-02-12; Hospital Research Ethics Committee 2012-153). The principal investigator interviewed the participants at the hospital where their colonoscopy was performed. *Delay* in seeking help was defined as the time interval between the onset of symptoms and the first medical consultation.

Table 5.1: Demographic characteristics of participants and symptoms experienced

Sl. No		Frequency (n)
1	Country of birth	
	Australia	10
	England	6
	Europe	3
2	Age groups (years)	
	30–40	3
	40–50	3
	50–60	3
	60–70	6
	70–80	4
3	Relationship status	
	Married	14
	De facto	1
	Single (never married)	1
	Separated/divorced	3
4	Medical diagnosis (n=19)	
	Crohn's disease	3
	Volvulus	1
	Polyps	7
	Diverticulitis	3
	Internal haemorrhoids	3
	IBS	2
5	Private health cover	
	Yes	10
	No	9
6	Occupational status	
	Retired	3
	Currently working	16
	Tradesman	7
	Farmer	2
	Driver	3
	Professional	3
	Baker	1
7	Symptoms	
	Rectal bleeding	11
	Bloating	6
	Abdominal pain	7
	Burning sensation	2
	Constipation	8
	Weight loss	4
	Diarrhoea	7
	Flatulence	2
	Alternating diarrhoea and constipation	2
8	Time interval from symptom onset to help seeking	
	1 week–1 month	7
	1.1–3 months	2
	3.1–6 months	4
	6.1–18 months	2
	≥18 months	4

5.4.2 Interviews

The interview schedule was semi-structured and the questions were open-ended. The semi-structured interview style was adopted to cover the key themes of the theoretical framework while allowing the participants to discuss other issues that were relevant to their symptoms and their decision to seek help for the symptoms. The first part of the interview schedule comprised the background questions, including the participants' age, information about their lower bowel symptoms, marital status, occupation and private health insurance. The second part of the schedule comprised questions about their symptoms and help-seeking experiences and was based on the literature and guided by the theoretical framework of Andersen's Model (see Table 5.2).

Table 5.2: Interview guide based on the Andersen's Model of Total Patient Delay

Stage	Important questions
Appraisal delay	What symptoms did you have before you were diagnosed? What was your initial reaction to the symptoms you experienced? What was your interpretation of the symptoms? Did you speak with anyone (family/friends) about the symptoms?
Illness delay	What did you do about the symptoms? What were your reasons to consult a GP? Did anyone encourage you to see your GP? If yes, who was it and what did they say? Do you have a family history of bowel cancer?
Behavioural delay	How long was it from when you first had symptoms until you went to see your GP about them? Was there any specific reason to wait before you saw your GP? What finally led you to see your GP?
Scheduling delay	How was your first appointment with the GP? What did the GP tell you about your symptoms?
Treatment delay	Were you referred to a specialist or for colonoscopy when you first went to see your GP about your symptoms? How long was it from the time of referral for colonoscopy until you had colonoscopy?

At the start of each interview, the objective of the study was reiterated and the participants were reassured about the confidentiality of the interview data. To offset any potential anxiety, the participants were informed that the research was voluntary and that their participation or lack thereof would not affect their on-going or future treatment. Written informed consent was obtained from all participants before the interviews commenced. Each interview lasted 30–40 minutes. The interviews were conducted in a respectful, empathetic and non-judgemental manner. The researchers relied solely on patients' retrospective

accounts of their experiences and did not validate the responses with their health practitioners. The interviews were audio-recorded with the patients' permission and were subsequently transcribed verbatim.

5.4.3 Data analysis

The interviewer (DO, PhD student), was also the principal investigator in this research, had background in clinical medicine and qualitative research. The interviewer's clinical experience was useful in understanding the participants' concerns. The other researchers involved in the data analysis (MJ, AM, Thesis supervisors) are experts in qualitative research with a background and experience in public health research and clinical medicine. The researcher (DO) took field notes and audio-recorded the interviews so he could reflect on the participants' responses at a later stage. The information obtained during the interview was double-checked with the participants to ensure that it had been correctly understood and interpreted, and that the information narrated by the participants had been noted correctly (also known as member checking).

As with Study 2 (See Section 4.3.4) data was analysed thematically. The final themes retained were those that generated consensus from all team members and that were supported by the data. Further, the data were supplemented by direct quotations from the participants wherever possible. After all of the themes had been identified, they were clustered within the different stages of Andersen's Model. Direct quotations from the participants were used to support the themes where required. Details about the steps involved in identification of the themes are provided in Section 6.3.4 of the thesis.

5.5 Results

The age of the participants varied from 36 to 78 years (mean age 58.4 (\pm 13.87) years). The period between the onset of symptoms and first seeking medical advice ranged between one week and 30 years (median 16 weeks); however, most of the participants (n=13/19) had sought advice within the first six months of their symptom onset, and two participants had sought advice between six and 18 months. The remaining four participants delayed seeking advice for eight to 30 years. The most common initial symptoms noted were change in bowel habit (most frequently a change to loose stools), rectal bleeding, bloating and abdominal pain (see Table 5.1).

5.5.1 Appraisal delay: themes

5.5.1.1 Misinterpretation of the symptoms

Most of the participants (n=17/19) did not initially believe the symptoms were serious because they were uncertain of the cause of their symptoms or were not concerned about them. Only two participants were alarmed when they first noticed blood on their toilet paper. The presence of a vague symptom (change in bowel habit) or the absence of a symptom such as abdominal pain slowed down the symptom appraisal process. A few participants (n=4/19) stated that if they had experienced pain, they would have consulted their GP earlier:

'You know unless I had a lot of pain in that particularly area, it's never been a big deal. I've had lots of friends in the army who had all sorts of symptoms, similar symptoms, but they were still fine'. Participant 8, 63 years, diagnosed with benign polyps.

Rectal bleeding was mostly attributed to haemorrhoids, and other bowel symptoms (including rectal bleeding) were attributed to ageing. A few participants (n=4/19) attributed their symptoms to eating habits or changes in diet. These participants identified food products such as white bread, dairy products, fatty foods and inconsistent dining habits as a cause of their symptoms. One participant attributed his symptoms to excessive alcohol intake in the past. Some participants (n=3/19) believed that their symptoms were side effects of medications for other illnesses (such as pain killers or anti-diabetic drugs):

'I just kept telling myself it was haemorrhoids; hmm don't worry about it. Oh nothing in particular (ha ha) ... other than the ring of fire'. Participant 2, 70 years, diagnosed with polyps

Some participants (n=4/19) seemed to have a limited understanding of their symptoms and attributed them to physical stress, exposure to harmful chemicals in their respective occupations, or to existing medical conditions (e.g., hernia or stomach cramps):

'I had worked in the construction stream ... it was more of lifting stuff ... I thought it might have been because of that ... yeah I was lifting a lot ... I've strained muscle sometimes, that's what I thought originally'. Participant 4, 38 years, diverticulitis

5.5.1.2 Symptom disclosure to a significant someone

Symptom disclosure to a significant someone had a mixed effect on participants' decision to seek medical advice. Nearly one-third of the participants (n=7/19) sought help after discussing their symptoms with a significant someone. In contrast, a few participants

(n=2/19) were reassured after discussing their symptoms with their friends and delayed seeking help. For instance, one participant—a truck driver who did not seek timely help when his fellow truck drivers admitted to experiencing similar symptoms—attributed his symptoms to prolonged driving sessions. Three participants were too embarrassed to disclose their symptoms to others, as they considered it a private issue:

'I also spoke to a couple of other drivers to check if they had constipation too and a lot of them said yes they did have constipation at times, and also [a] lot of them said they had diarrhoea occasionally and like they had to go to the toilet 3–4 times in a couple of hours. That sort of thing ... yeah ... they said oh don't worry about it ... it's just a condition of our job ... Ha ha ha'. Participant 11, 75 years, IBS

5.5.1.3 Symptom exacerbation

Factors such as worsening of symptoms and the appearance of additional lower bowel symptoms facilitated the appraisal process.

5.5.2 Illness delay: themes

5.5.2.1 Non-persistent symptoms

One-quarter of the participants (n=5/19) did not seek timely medical attention, as the symptoms were non-persistent or periodic, improved with home remedies (e.g., diet) or because they were not concerned about the symptoms. One patient delayed going to a GP after experiencing the symptoms for several years, as he had accepted them as part of his life. In contrast, another patient sought advice after experiencing the symptoms for around one month, as they were recurrent. One participant assumed that his diet was responsible for his constipation, which in turn caused haemorrhoids:

'So you change the diet and the symptoms improve, you start eating the crap all over again. It has occurred intermittently, you know, because I used to strain with my bowel movement, umm ... that put pressure on haemorrhoids and subsequently I changed my diet and habits and it worked'. Participant 13, 65 years, polyps

After appraising the illness, some participants decided not to seek medical advice, as they sought help from community pharmacies for their symptoms. After the symptoms had resolved with OTC medications, they did not consult a GP:

'I had to go to the chemist to get some sort of ... what they are called I'm not sure ... and they sort of relieved it a bit and ... aah ... I normally would take Eno if I felt that the

discomfort was from eating. It really helps me. There nothing else I would take'. Participant 14, 66 years, Crohn's disease

Some participants sought advice when the symptoms persisted despite diet modification (n=2), and others because of a family history of bowel cancer (n=3/19). One participant sought advice when he realised that his symptoms were causing him inconvenience:

I just got tired of waking up and feeling like shit ... bad ... you know it wasn't a good quality of life and no matter what you do you always have that feeling. You try taking different things but it doesn't get any better and people suggested that it could be due to bread or something, so I changed my diet, just eating veggies and fishes and stuff and I didn't feel any better. So I went to my GP'. Participant 1, 38 years, Crohn's disease

5.5.2.2 Encouragement to seek advice from female family members

A female family member (spouse or mother) played an important role in encouraging men to seek medical advice. A number of participants (n=7) were encouraged to seek advice for their symptoms by female family members. Some participants (n=6/19) acknowledged that if they had not received the encouragement, they would have not consulted a GP for their symptoms:

My wife said to me "go to the doctor, go to the doctor". Huh! Then I had a few days off and then it got just worse ... yeah I had it for few days and then my wife said that I should go to the doctor'. Participant 4, 38 years, diverticulitis

5.5.2.3 Help seeking by family members

The help-seeking behaviour of other family members also influenced men's decision to seek medical attention. One participant mentioned that his father, who was over 60 years of age and had chronic health conditions, never went to the doctor in his entire life, so he too never appreciated the value of seeking medical advice for his symptoms. In contrast, one participant mentioned that he consulted a GP frequently because everybody else in his family did the same.

5.5.3 Behavioural and scheduling delay: themes

5.5.3.1 Failure to arrange time to seek medical advice

One-quarter of participants (n=5/19) acknowledged that they did not seek timely medical advice because of their working hours, inability to arrange a visit to a GP or because visiting a GP was a low priority because of other social and personal commitments. Another participant stated that he felt it was inappropriate to consult a GP every time he had a symptom, mainly because visiting a GP was time-consuming:

'Well, at that stage my son had this brain tumour. He was under treatment and of course my brother had cancer too. So a lot was happening in our lives and I was also working in shifts. Aah ... so yeah we had a busy life ... trying to keep the family going both financially and health wise'. Participant 16, 61 years, polyps

5.5.3.2 Embarrassment about seeking medical advice

Two participants mentioned that they were too embarrassed to visit a GP for rectal bleeding, and therefore once the symptoms had subsided, they dismissed the idea of consulting a GP. A few participants (n=3/19) mentioned that they had wanted to arrange an appointment with a GP, but as the symptoms improved with OTC medications, they delayed going. One participant mentioned that he had not liked taking medications since childhood, and he did not expect a GP to do anything extraordinary about the symptoms, so he delayed arranging an appointment:

'What would the doctor do? Just order some tests, write me some antibiotics, or recommend changes in my diet, or tell me not to drink too much'. Participant 1, 38 years, Crohn's disease

One participant visited a GP for a solution to belly fat, which he assumed was the cause of bloating, while three participants mentioned that they were not too concerned about their symptoms and discussed them with their GP during a regular consultation for another reason. Persistence of symptoms (n=4/19) and the appearance of pain or exacerbations of symptoms were other triggers for seeking medical advice (n=9/19):

'Oh I had some stomach acid issues before and as I said I probably just ate something and it probably would set it off and it will be there for a couple of days and then I'd be fine and then that guy sort of attitude that I'd be all right but eventually it didn't get any better so I thought I'd better go and get this checked out'. Participant 1, 38 years, Crohn's disease

5.5.3.3 Fear of diagnosis and investigation

Two participants who had experienced symptoms in the past and had not sought medical advice consulted their GP only after a family member had been diagnosed with polyps and bowel cancer. Two participants cancelled their appointment with a GP because they were apprehensive about the invasive nature of the investigations. One participant mentioned that he was scared of being anaesthetised:

'Yes I probably did (delay). I guess just the thought of the actual procedure. I didn't like the idea of having it; I felt that it was invasive'. Participant 10, 73 years, IBS

A few participants delayed their appointment because they were anxious about cancer diagnosis (n=4):

'I was concerned it might be something else ... umm because I had heard a bit about bowel cancer'. Participant 1, 38 years, Crohn's disease

One participant deferred his appointment with a GP based on the assumption that the GP's waiting room would be full of flu patients during the winter, and he did not want to be exposed to infections.

5.5.4 Treatment delay

Treatment delay relates to the time elapsed between the patient's first GP visit and the establishment of a diagnosis following a colonoscopy. In the current study, this stage was relatively shorter for most participants compared with other stages of delay. All participants, except one, acknowledged that their first point of contact for seeking medical advice for their symptoms was their GP, who examined and referred them to the hospital or for a colonoscopy in the same meeting. However, the scheduling of a colonoscopy ranged from three weeks to five months for different participants.

Various factors that facilitated or impeded help seeking for these symptoms based on the various stages of delay proposed by Andersen's Model are presented in Table 5.3.

Table 5.3: Factors facilitating or delaying help seeking

<p>Appraisal delay</p> <p>Inhibiting factors: Symptoms without pain; misinterpretation of symptoms (attributing symptoms to improper eating habits or to certain types of foods, excessive alcohol intake, co-existing medical conditions, side effects of medications for other conditions and professional liabilities such as lifting heavy weights or exposure to harmful chemicals); embarrassment associated with discussing the symptoms with a GP.</p> <p>Facilitating factors: Exacerbation of symptoms or appearance of new symptoms.</p> <p>Factors with mixed responses (both facilitated and delayed the appraisal): Discussing symptoms with family or friends (significant others).</p>
<p>Illness delay</p> <p>Inhibiting factors: Intermittent symptoms; improvement in symptoms with changes in diet; belief that symptoms would resolve spontaneously; OTC medications; belief that visiting a doctor was time-consuming; poor help-seeking behaviour of family members about their symptoms.</p> <p>Facilitating factors: Encouragement by a female family member; symptoms disturbing routine life or causing embarrassment; other family members seeking regular medical advice.</p>
<p>Behavioural and scheduling delay</p> <p>Inhibiting factors: Failure to arrange time to visit a GP; professional and social commitments; embarrassment about seeking advice for rectal bleeding; relief of symptoms from OTC medications; reticence to invasive investigations and anaesthesia; fear of cancer; low expectations from a GP for any help with the symptoms.</p> <p>Facilitating factors: Persistence or exacerbation of symptoms; appearance of new symptoms or pain; family history of bowel cancer.</p>

5.6 Discussion

5.6.1 Principal findings and comparison with previous studies

In the current study, the researchers found that prolonged delays in help seeking with regards to lower bowel symptoms were common among men diagnosed with chronic colorectal conditions or benign bowel pathology. Almost one-third of the participants (n=6/19) delayed to seek medical advice for a relatively longer period of time (>6 months) in Study 3. The first stage of delay outlined in Andersen’s Model—appraisal delay—contributed to the longest delay in the pathway to diagnosis, consistent with the findings of Study 2 where men who did not consider their symptoms serious enough to warrant medical attention did seek advice for their symptoms. This finding was also consistent with previous studies in literature, which identified appraisal delay as the single largest contributing factor to patient-related delay^(18, 22, 24–26). Factors such as lack of knowledge about the potential risks associated with the symptoms or potential cause of symptoms, misinterpretation of symptoms and attribution to common causes such as their eating habits and other co-existing conditions prolonged this stage of delay. In contrast, factors such as exacerbation of symptoms or appearance of additional symptoms such as pain shortened this stage of delay.

These findings were also supported by previous research studies exploring the reasons for delay in help seeking^(26, 27). The findings related to appraisal delay were further supported by findings from a recent study on Australian adults (n=1592) by Courtney et al.⁽³¹⁾, in which the authors observed that men who regarded their rectal bleeding as significant of concern or of potentially life-limiting condition were more likely to seek medical advice. This lends support to the call for health education campaigns to improve men's awareness of lower bowel symptoms. The factors related to the other phases of delay in Andersen's Model—illness, behavioural and scheduling delay—also contributed to a delay in diagnosis in Study 3; however, treatment or system delay played little role in the delayed diagnosis. With regards to system delay or the hospital-related delay, most participants in the current study said that their GP investigated them and referred them sooner rather than later. The only cause of delay for some participants in this stage of the model (corresponding to the fifth stage of Andersen's Model) was in the scheduling of a colonoscopy resulting from long waiting lists in public hospitals. This is in contrast to some previous studies, which found that factors related to the healthcare system delay contributed to a diagnostic delay in cancer⁽²⁵⁾. This finding was now validated with the hospital medical records.

The findings in Study 3 also support Molassiotis's suggestion⁽²⁵⁾ that help-seeking behaviours for perceived cancer symptoms are non-linear i.e. people experiencing symptoms may not always move unidirectional from one stage of delay to the next until they are diagnosed and treated. For example, in the illness delay stage in the current study, when participants in the current study (Study 3) were unsure about seeking medical advice for a certain period of time, the inconvenience in their lives or disturbed routine caused by the symptoms pushed them back to the previous stage of delay-appraisal to reconsider their symptoms. Similarly, participants in the behavioural delay stage who were not very sure about scheduling an appointment with a GP reconsidered their decision and decided in favour of help seeking because of the exacerbation of symptoms or the appearance of new symptoms (see Figure 5.2). This suggests that the process of transition from one stage of the model to the next is not always unidirectional⁽²⁵⁾ and is consistent with the findings of de Nooijer et al.⁽²⁴⁾ who reported similar observations on the nonlinearity of participants' transit through the various stages of Andersen's Model.

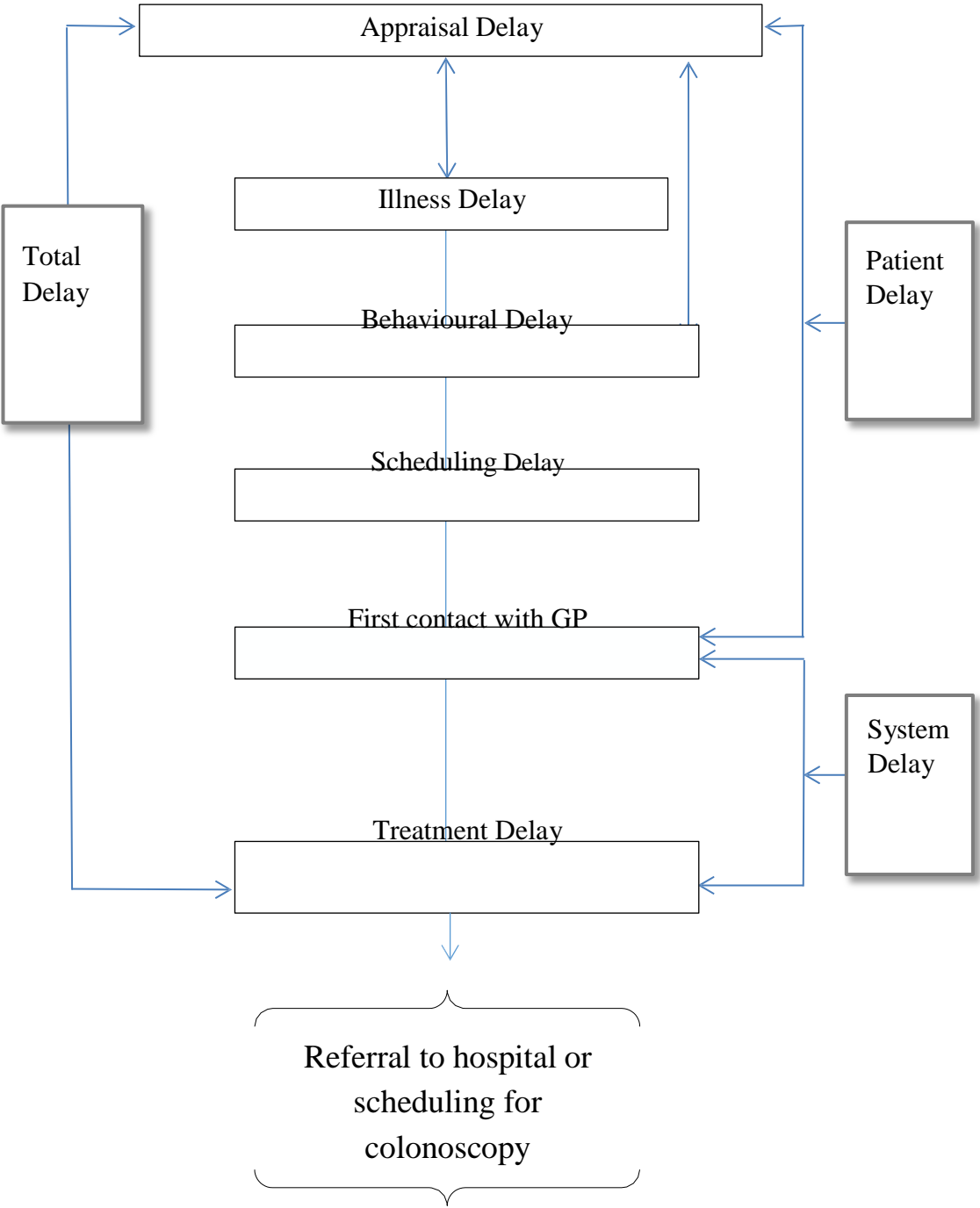
Another interesting factor, which led to delay in help seeking in Study 3, was the participants' attribution of symptoms to their occupational hazards. For instance, one participant, who was a construction worker, attributed his rectal bleeding to lifting heavy weights, while another participant, who had worked in the military for several years in the past, attributed his symptoms to harmful chemicals in the military areas and war zones. This

findings gives an impression that men have a limited understanding of the pathophysiology of lower bowel symptoms; however, it needs to be explored further why men find it convenient to attribute their symptoms to causes other than medical (Figure 5.2). At the same time, it needs to be considered that the current study did not directly evaluate participants' knowledge about the potential causes of bowel pathology or the role of the symptoms in bowel pathology.

As mentioned in the findings, a few participants (n=3/19) had mentioned that they delayed seeking advice because they were unsure whether a GP would be able to help with their symptoms or would simply refer them to a specialist. These men had arrived at these conclusions based on their previous experiences with GPs. Similar findings were observed in Study 2 of this thesis as well and brings out the commonality of the reasons for delay in men diagnosed with benign conditions and in those who never sought help. Given that only 3.4%–11.1% of individuals experiencing rectal bleeding are diagnosed with CRC⁽³²⁾, GPs play an important role as gatekeepers to specialist healthcare. This is further supported by the results of the current study, which suggest that there is little to no delay in patients' referral by a GP. Participants reported fear of cancer diagnosis and invasive procedures such as a colonoscopy as other causes for the delay in seeking medical attention. Systematic and qualitative reviews in the past have highlighted fear of cancer or fatal incurable diseases and embarrassment associated with investigations as barriers to help seeking in patients experiencing painful lower bowel symptoms^(26, 33). As the symptoms of benign and malignant colorectal diseases are similar, some participants' GPs may have suspected cancer; however, the researchers did not verify this.

Another theme that emerged in Study 3 mentioned as a reason to delay help seeking or for failure to arrange time to visit a GP was men's occupational commitments. This finding was supported by Fell et al.'s⁽³⁴⁾ observations that long working hours may act as a barrier to seeking medical advice in Canada, particularly in those working >45 hours per week during the daytime. Given that full-time employees in Australia usually work around 7.6 hours per day or 38 hours per week⁽³⁵⁾, this could be a barrier to help seeking, and this was supported by findings in the current study. However, this needs further investigation and if professional commitments are established as major barriers to help seeking in cross-sectional studies or studies establishing causal relationships between hours of employment and inability to visit a GP, future research should be directed at identifying ways of offering greater flexibility at work places to facilitate timely help seeking among men.

Figure 5.2: Help-seeking pathway adapted from Andersen et al.'s (1995) general model of total patient delay



5.6.2 Limitations

Although Study 3 provides insights into the reasons for delayed help seeking among men diagnosed with benign colorectal diseases, the findings are not generalisable, as the sample was small and was not representative of the population. Some participants delayed for periods ranging from a few months to several years before seeking medical advice, and the information obtained from them is subject to recall bias^(25, 31). Given that the data collected in the study were the participants' narratives of their experiences and there was no verification from past medical records, there may be some inaccuracies in the timing of events along the help-seeking pathway.

5.6.3 Implications for policy and research

A number of steps need to be taken to facilitate timely help seeking in men with regards to their lower bowel symptoms. Different interventions may be required to target individuals at different stages of delay based on Andersen's Model.

5.6.3.1 Potential interventions

The study found that 'appraisal delay' stage in Andersen's Model contributed the most to the total delay in seeking medical advice and establishing a diagnosis because of a lack of knowledge about the symptoms and misinterpretation of the symptoms. This suggests that appraisal delay is a significant area for potential interventions to encourage timely help seeking among men. Education and awareness about diminished HRQoL, risk of absence from work, loss of productivity and risk of CRC associated with persistent lower bowel symptoms should be the prime focus of public health interventions. It has been argued that in some individuals, the availability of information may evoke cognitive dissonance (inconsistency in thoughts, beliefs, or attitudes, especially as relating to behavioural decisions and attitude change) thereby leading to devaluing the information or ignoring the symptoms^(36, 37). Therefore, information should be communicated through channels that are more likely to facilitate help seeking. Some participants suggested that embarrassment associated with discussing their symptoms with a GP was a cause of delay. In this regard, it might be helpful if the GP assumed a more proactive role in asking men about their lower bowel symptoms during routine medical visits.

Participants often delayed seeking medical advice when the symptoms resolved temporarily with OTC medications. Given that community pharmacies are the immediate point of care to access health services for some men, pharmacists can play a major role in referring patients with persistent symptoms to a GP for timely investigation and diagnosis through the use of

questionnaire-based screening tools ⁽³⁸⁾. It was also found that, in several cases, female family members played an instrumental role in encouraging men to seek timely medical advice. Thus, public health interventions to encourage timely help seeking among men may also be targeted at female partners as a confidant of their male partners or family members. A few men also followed value judgement to guide their help-seeking behaviour, which suggests that educational and awareness campaigns directed at the family rather than individual patients may help to encourage timely help seeking among men. The role of the family in encouraging men to seek timely advice for their symptoms may offer an important opportunity for early diagnosis.

Most participants delayed seeking help in fear of the diagnosis, as they considered cancer diagnosis a death sentence. In this regard, information about the improved prognosis of cancer through early diagnosis and treatment should be made available via public health campaigns to alleviate the fear of cancer among men. Given that the majority of participants did not report any delay in the diagnosis or treatment phase, it is difficult to suggest any intervention pertaining to this stage of Andersen's Model.

5.7 Conclusion

Study 3 in this thesis highlighted the help-seeking experiences of 19 men diagnosed with chronic or benign colorectal conditions in WA. Most of the factors associated with the delay in seeking medical advice for lower bowel symptoms were related to appraisal delay and were consistent with barriers to help seeking identified in Study 2. Other delaying factors were lack of trust in GPs, fear of cancer diagnosis and failure to arrange time to visit the doctor. The facilitators and barriers identified in this study suggest that men's help-seeking habits are amenable to change via interventions within the public and primary healthcare systems. The results of this study emphasise the need to encourage men to seek timely medical advice for their lower bowel symptoms. The next phase of research in this thesis will explore the help seeking experiences on men diagnosed with CRC.

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Chapter 6: Exploring the Help-Seeking Experiences of Men Diagnosed With Colorectal Cancer: A Qualitative Study (Study 4)

Publication

This study has been published in the *European Journal of Cancer Care* as shown below.

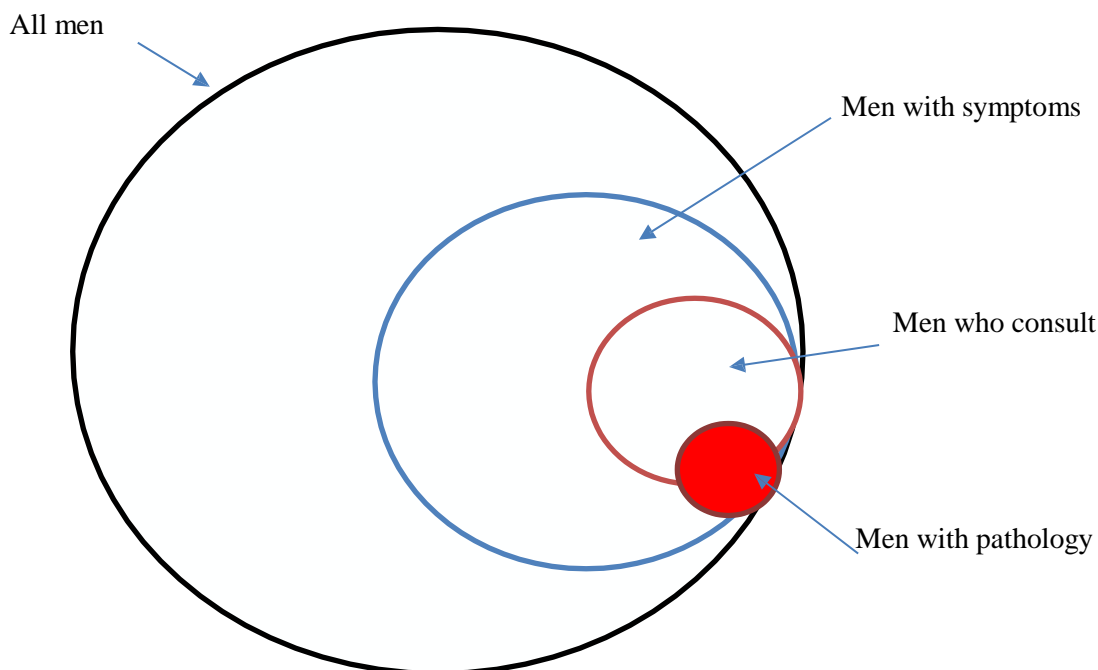
Citation

Oberoi DV, Jiwa M, McManus A, Hodder R. Help-seeking experiences of men diagnosed with colorectal cancer: a qualitative study. *European Journal of Cancer Care*. 2014. DOI: 10.1111/ecc.12271.

6.1 Summary

Study 4 forms the final step of the trajectory. It aimed to explore the help-seeking behaviour of men (in regards to their lower bowel symptoms) diagnosed with CRC. This is the last of the four studies conducted as part of this thesis. Study 4 is the fourth study conducted as part of this thesis and is represented by a coloured circle in Figure 6.1.

Figure 6.1: Schema of the thesis—Study 4 (highlighted)



Background: Advanced-stage diagnosis of CRC leads to poor prognosis and reduced survival rates.

Objective: Study 4 aimed to explore the reasons for diagnostic delays in a sample of Australian men with CRC.

Methods: Semi-structured interviews were conducted in a purposive sample of 20 males diagnosed with CRC. Data collection ceased when no new data emerged. Interviews were audiotaped, transcribed and thematically analysed using Andersen's Model as the theoretical framework. Most participants had experienced lower bowel symptoms prior to diagnosis.

Results: The barriers to seeking timely medical advice were mainly attributed to the misinterpretation of symptoms, fear of cancer diagnosis, reticence to discuss symptoms or consult a GP. 'Patient-related' delays were more common than delays attributable to the healthcare system. In many instances, delays resulted from men's failure to attribute their

symptoms to cancer and subsequently delayed their diagnosis. Data regarding patient delays fit within the first four stages of Andersen's Model. Treatment delays were a minor cause for delayed diagnosis and delays in referral and scheduling for a colonoscopy were among the system delay factors. Study 4 supports the view that delays in CRC diagnosis are common.

6.2 Background and objective

Past studies on various cancers have revealed both patient- and system-related (primary care and hospital-related) delays in the lead up to the diagnosis, thus helping to identify the facilitators and barriers to seeking help⁽¹⁻⁵⁾. As evidenced through Chapters 1 and 2 in this thesis and from past studies, there is limited information on help-seeking experiences of men in regards to lower bowel symptoms prior to CRC diagnosis⁽⁶⁾. The first four stages of Andersen's Model⁽⁷⁾ attribute the delay to patients, whereas the fifth stage focuses on healthcare providers. Published studies that have used Andersen's Model as a theoretical framework to analyse delayed diagnosis for different cancers have determined that patient-related delays prevail⁽⁸⁾. In a systematic review of the factors affecting pre-hospital delays in the diagnosis of CRC, Mitchell et al.⁽⁹⁾ observed behavioural factors such as non-recognition of symptom severity, and other factors such as the lack of knowledge either about the disease or the availability of screening programmes, and symptom denial leading to increased delays. In another study, people who self-diagnosed or purchased OTC drugs also delayed seeking medical advice from a doctor⁽⁹⁾. In a recent study on the help-seeking behaviours of Australian adults with regards to symptoms of CRC, Courtney et al.⁽¹⁰⁾ found that people delayed seeking advice because they did not recognise the seriousness of their symptoms; they denied the symptoms, were embarrassed about the symptoms or believed that the symptoms would resolve spontaneously. However, most of the studies included in the review were either observational (prospective/retrospective) or cross-sectional, and only two were based on qualitative interviews^(5, 11, 12). Further, although Australia has one of the highest incidences of CRC in the world⁽¹³⁾, a literature review by Oberoi et al.⁽¹⁴⁾ suggested that few studies have been carried out on the Australian population in the past four decades^(10, 15-20).

Chapters 1 and 2 in this thesis provide an overview of the underlying issue about men's help-seeking behaviour and reasons for delay from literature. Study 2 in this thesis represented a stage along the trajectory where the participants experienced the symptoms but did not seek help, while in Study 3 participants had sought medical advice at some point but were diagnosed with chronic or benign conditions. Study 4 in this thesis sought to identify the potential reasons for delay between the onset of symptoms and the diagnosis of CRC in a sample of Australian men using Andersen's Model of Total Patient Delay as the theoretical framework.

6.3 Methods

6.3.1 Theoretical framework

As with studies 2 and 3, Andersen's Model was used as a theoretical framework in the study to guide the development of the interview schedule and the data analysis. The model, as discussed in previous chapters, outlines five potential stages of delay, including patient-related delays in seeking help for their symptoms, and system- or hospital-related delays in the initiation of treatment ⁽⁷⁾.

6.3.2 Operational definitions

Delay: Participants were asked about the time interval between the onset of symptoms and the first medical consultation. Andersen's Model ⁽⁷⁾ did not provide any operational definition of patient delay. Pack and Gallo ⁽²¹⁾ defined patient delay as a delay of three months or more before seeking medical advice following the onset of cancer symptoms.

6.3.3 Sample

The participants included 20 adult men living in WA who had been diagnosed with CRC within the past three months, and who had given informed consent. Purposive sampling was used to achieve diversity in participants' age groups, social backgrounds and the stage of cancer at diagnosis in order to obtain a range of perspectives.

6.3.4 Data collection and analysis

Upon obtaining ethics approval from the relevant institutional human research ethics committees, men diagnosed with CRC were invited to participate in this study. All of the participants received an information sheet and a consent form from their consultant surgeon. The participants gave their written consent to be interviewed, for the interviews to be tape recorded and for the transcripts to be analysed and de-identified excerpts to be published. Completed forms were provided to the principal investigator. Participants who consented to participate were interviewed between February and July 2013.

The data collection technique was similar to that used in studies 2 and 3 of this thesis. The interviews were semi-structured and open-ended, and each interview lasted for around 25–35 minutes. Before the interview commenced, the objective of the study was restated, and the participants were assured about the confidentiality of the interview data (see Sections 4.3.3 and 4.3.4 for other details about data collection methods). The participants were asked to give an account of their experiences of lower bowel symptoms from onset until CRC

diagnosis. The interviewer (DO, PhD Student) then asked the participants a list of questions based on the five stages of Andersen's Model (see Table 6.1). Data collection ceased once data saturation was achieved, no new themes emerged from participants' responses and the collection of data did not provide any new information because the participants reported similar perspectives of their experiences. The interviewer verified the interview data with the participants to ensure accuracy of the information collected and interpreted (member checking).

Transcription and analysis: The interviews were transcribed verbatim and were analysed after each interview. The principal investigator read and reread the transcripts four times to familiarise himself with the data and decipher the emergent themes. The transcript text was coded and mapped against the five stages of the model: appraisal, illness, behavioural, scheduling and treatment delay. The interview guide formed the framework for analysis. The emergent themes were then discussed with other team members (MJ and AM, Thesis Supervisors), who were both qualitative research experts and one is an experienced clinician. The themes were evaluated in the context of the data by all researchers, and the themes that failed to reach consensus were eliminated or revised. The data were revisited in the context of the revised themes, and only those themes that strongly supported the interview data were retained. The overarching method of analysis was the framework method^(38, 39). The themes were identified using a hybrid deductive and inductive approach^(38, 40). The pre-existing theoretical constructs from the analytical framework (Andersen's Model of Delay) were used deductively and, thereafter the data was revisited using inductive approach to examine any text that was not already associated with a theme. As the data collection and analysis was largely based on a pre-existing analytical framework, the deductive approach dominated the inductive approach in the identification of main themes.

Steps in the identification of themes were as follows

- x Review of data through the analytical framework (AMTPD) lens: The use of analytical framework allowed data to be labelled into manageable chunks (paragraphs, sentences and phrases) for subsequent exploration. The template for analysis was developed a priori based on the research objective, interview schedule, and the five stages of delay described in Andersen's model- appraisal delay, illness delay, behavioural delay, scheduling delay and treatment delay. Colour coding: The transcripts were summarised by outlining the key points made by the participants in response to the interview questions. The chunks of data from the transcripts were marked-up/colour coded with codes from the analytical framework (the five stages of delay). Subsequently, the data (text from the transcripts) was rearranged and

sorted according to the relevant categories of the analytical framework using the simple cut and paste technique. After coding the first few transcripts the results were discussed with the PhD supervisors in regular meetings for the suitability of the codes.

- x Chart formation: After the text was grouped into relevant categories, the charts were formed for each theme with responses from multiple participants. The charts included verbatim quotations that seemed to be important and relevant to the grouped text. Quotations were cut out from transcripts and pasted together under corresponding categories. Similarities and differences between separate groups of data were emerging at this stage. Literature was reviewed to aid the identification of themes.
- x Contextual understanding of summarised data: The summarised data, accompanied the quotations, was recoded within the wider context of each case and hyperlinked to the complete transcript from respective participants, for the purpose of referring back to the transcript to understand the context within which the information was provided by the participants.
- x Mapping and interpretation: The research objectives and the analytical framework guided the mapping and the interpretation of the data. This was followed by the identification of themes and patterns in the data. The text passages that were related to major themes and the quotations that pertained to each of the identified themes were cut out and sorted into sub thematic categories. Repetitive quotations that were quite similar were later removed and only unique quotations were retained to provide support to the themes. The quotations were de-identified. Analysis of the data ceased when theoretical saturation was achieved and no new themes were identified.
- x The themes (major and minor) were summarised on a separate document. The data (transcripts) were revisited in the light of these themes. The repetitive themes were merged.

Table 6.1: Interview guide based on the five stages of Andersen’s Model of Total Patient Delay

Stage	Important questions
Appraisal delay	<ol style="list-style-type: none"> 1. What symptoms did you have before you were diagnosed? 2. What was your initial reaction to the symptoms you experienced? 3. What was your interpretation of the symptoms? 4. Did you speak with anyone (family/friends) about the symptoms?
Illness delay	<ol style="list-style-type: none"> 1. What did you do about the symptoms? 2. What were your reasons to consult a GP? 3. Did anyone encourage you to see your GP? 4. If yes, who was it and what did they say? 5. Do you have a family history of bowel cancer?
Behavioural delay	<ol style="list-style-type: none"> 1. How long was it from when you first had symptoms until you went to see your GP? 2. Was there any specific reason to wait before you saw your GP? 3. What finally led you to see your GP?
Scheduling delay	<ol style="list-style-type: none"> 1. How was your first appointment with the GP? 2. What did the GP tell you about your symptoms?
Treatment delay	<ol style="list-style-type: none"> 1. Were you referred to a specialist or for colonoscopy when you first went to see your GP for your symptoms? 2. How long was it from the time of referral for colonoscopy until you underwent a colonoscopy?

6.4 Results

Of the 20 participants, the majority had completed high school and two were tertiary educated. Twelve participants were retired. Almost all of the participants (n=19/20) had public health cover with no private health insurance, and only one participant had private health insurance. The mean age of the study participants was 62.17 (\pm 15.7) years and the age range 27–87 years. Among the symptomatic participants, the mean time interval between symptom onset and first medical consultation was 7.36 (\pm 6.95) months, and the median time interval was 5.5 months. The time interval between symptom onset and consultation ranged from zero days (for a participant who attended an Emergency Department following major rectal bleeding) to two years. The characteristics of the study participants and their various symptoms are shown in Table 6.2.

Table 6.2: Characteristics of study participants and their symptoms

Sl. no		Frequency (total number of participants) (%) n=20
1	Country of birth	
	Australia	13
	United Kingdom	5
	New Zealand	1
	South Africa	1
2	Age groups (years)	
	20–40	1
	41–60	6
	61–80	11
	≥81	2
3	Relationship status	
	Married	10
	De facto	2
	Single (never married)	2
	Separated/divorced/widowed	6
4	Type of cancer	
	<i>Rectal cancer</i>	9
	Stage 1	4
	Stage 3	3
	Recto-sigmoid Stage 2	2
	<i>Colon cancer</i>	11
	Stage 1	6
	Stage 2	3
	Stage 3	1
	Stage 4	1
5	Private health cover	
	Yes	1
	No	19
6	Occupational status	
	Retired	9
	Occupational background	
	Tradesman/labourer	9
	Farmer	2
	Driver	2
	Professional	4
	Carpenter	2
	Chef	1
7	Symptoms	
	Rectal bleeding	15
	Bloating	1
	Abdominal pain	3
	Burning sensation	1
	Constipation	4
	Unintentional weight loss	2
	Diarrhoea	6

	Flatulence	2
	Alternating diarrhoea and constipation	1
	Tenesmus	2
8	Time interval from symptom onset to help seeking	
	1 week-1 month	2
	1.1-3 months	3
	3.1-6 months	6
	6.1-18 months	5
	>18 months	1

6.4.1 Appraisal delay

6.4.1.1 Participants' responses to symptoms

Most participants (n=18/20) were symptomatic in their pre-diagnostic period, presenting with one or more symptoms (diarrhoea, constipation, rectal bleeding, abdominal pain, fatigue or unintentional weight loss). Two participants did not experience any lower bowel symptoms. Participants' initial reactions varied and depended on the type of symptoms. Moreover, the nature and severity of symptoms shortened or lengthened the delay in seeking help. For example, one participant who experienced exacerbated symptoms sought emergency hospital service without any delay.

Intermittent episodes of rectal bleeding or change in bowel habit did not warrant help seeking, whereas a major episode of bleeding or bleeding accompanied by pain led the participants to immediately seek medical help. Many participants ignored the symptoms when they first appeared; however, they decided to seek help when the symptoms persisted, worsened or new symptoms appeared. Participants who associated their symptoms with a potential illness were relatively quick to seek help, thereby shortening the appraisal delay stage of Andersen's Model. Conversely, participants who misinterpreted their symptoms or did not perceive the symptoms as warranting medical advice waited longer to seek help (thereby lengthening the stage of appraisal delay). One participant said that he did not seek medical advice, although his symptoms persisted for months, as he believed his bleeding was due to haemorrhoids and would clear up spontaneously. A few participants (n=3/20) said that they did not consider their symptoms serious enough (rectal bleeding and change in bowel habit) to warrant medical consultation:

'It was going on for quite a long period of time and I thought it was just haemorrhoids and nothing else and one Easter Saturday I was getting ready to go shopping with my wife and before that I just went to the toilet and bang, I saw blood and it came from nowhere and it was all over in the toilet and the wall and so we went to the hospital'. Participant, 50 years, Stage 1 rectal cancer.

6.4.1.2 Misinterpreting the symptoms

Participants attributed their symptoms to common illnesses or benign ailments—for instance, rectal bleeding to haemorrhoids (n=11/20) and change in bowel habit to excess intake of alcohol (n=2/20), poor eating habits (n=2/20) and hot weather (n=1/20).

Bleeding was not a cause for worry in participants (n=6/20) who believed that it would clear up spontaneously and adopted the 'wait-and-see' approach or decided to buy OTC medications for their symptoms. The temporary relief provided by the medications further caused them to delay seeking medical advice:

'I'd take the laxative and I'll be all right. And then it would block again and I'll take this again and I'd be all right'. Participant, 80 years, Stage 2 colon cancer.

Nearly, a quarter of participants (n=6/20) believed that the nature and duration of their symptoms affected their decision to seek help. Two of these participants mentioned that they would have sought advice from a GP earlier if the bleeding had persisted for a longer duration. A few participants (n=4/20) believed that low-volume and intermittent episodes of rectal bleeding were indicative of less serious symptoms that did not warrant seeking medical advice.

Other participants (n=4/20) felt that poor eating habits and excessive alcohol or coffee intake were responsible for their abdominal pain and altered bowel habit. One participant acknowledged that the disappearance of symptoms, which he attributed to reduced coffee intake, encouraged him not to seek medical advice.

Almost half of the participants (n=9/20) attributed their symptoms to causes other than cancer, which reflected their inaccurate understanding of the risk factors of CRC:

'I didn't think about bowel cancer, no no ... well, there being no blood, I wasn't concerned, everybody has constipation to different degrees, or diarrhoea'. Participant, 72 years, Stage 1 colon cancer.

Some participants attributed their symptoms to other causes such as work-related issues (n=1/20), previous medical treatment (n=2/20) or side effects of on-going medications for comorbid conditions (n=1/20). One participant, who was a carpenter, presumed that his rectal bleeding had resulted from lifting heavy weights and decided to adopt the ‘wait-and-see’ approach. Another participant, who had undergone lower back surgery in the past, believed that his abdominal pain was originating from his back. An elderly participant aged over 85 years believed that his flatulence and diarrhoea occurred as a side effect of the prescription drugs he was taking for other conditions. Two other participants attributed their constipation to OTC pain relievers.

Two participants believed that cancer was something that could not happen to them. Periodic episodes of bleeding and the absence of pain further strengthened their belief that their symptoms were unrelated to cancer. Another factor associated with the interpretation of symptoms was the unawareness of being at risk. One participant aged 49 years mentioned that he believed CRC was a disease of old age and was not aware that young men were also vulnerable. He acknowledged that if he had been aware of the risk to younger men, he might have sought advice for his symptoms much earlier.

One participant mentioned that when he experienced rectal bleeding, he did not feel sick or weak. The absence of abdominal pain in some participants (n=4/20) led them to believe that their symptoms did not warrant seeking medical help. Some mentioned that if they had experienced pain along with the other symptoms, they might have seen the doctor immediately. One participant, who had earlier attributed his rectal bleeding to haemorrhoids, also admitted that sometimes men did not take symptoms seriously.

6.4.2 Illness delay

6.4.2.1 Disclosure of symptoms to significant others

Consulting a significant someone about symptoms was an important factor in deciding to seek medical advice. More than half of the participants (n=13/20) mentioned that they had spoken to a significant someone about their symptoms and their view regarding consulting a GP, including their spouse (n=8/20), mother (n=3/20), friends at work (n=1/20) and cousin (n=1/20). Two participants acknowledged that women were more proactive than men with regards to consulting a GP, which is why they felt it right to inform their wives about their symptoms. Only a few participants (n=4/20) had discussed their symptoms immediately or within a few days of their occurrence, while most participants did so only when the symptoms had persisted for several weeks to several months. One participant mentioned that he looked up his symptoms on the internet before speaking to his wife. Over a quarter of the

participants who had discussed their symptoms (n=7/20) acknowledged that they were encouraged to seek medical advice by their partners (n=5/20), friends (n=1/20) or cousin (n=1/20). Thus, discussing symptoms with a significant someone appeared to be a main factor that encouraged participants to seek advice about their bowel symptoms.

For two participants, their partners helped them in many ways, such as accompanying them to the doctor and a colonoscopy. Those who did not discuss their symptoms (n=5/20) cited reasons such as not having a spouse, maintaining privacy, not wanting to bother anyone about the symptoms, living alone or specified no reason. These people appeared to have delayed seeking medical advice for six to eighteen months longer.

6.4.2.2 Fear of cancer

The effect of fear of cancer on illness delay differed among participants. Two participants with a family history of CRC related their own symptoms with cancer and decided to seek medical advice when the symptom(s) persisted for a few days. One participant stated that he did not discuss his symptoms with anyone in the family for a long time until one of his cousins was diagnosed with bowel cancer. After speaking to his cousin, he went to the doctor. Two other participants with a family history of cancer delayed seeing a GP. One participant mentioned that fear of cancer diagnosis prevented him from seeking medical advice until the symptoms aggravated.

6.4.2.3 Exacerbation of symptoms

Some of the reasons cited by participants for seeking medical advice were more frequent episodes of bleeding (n=2/20), persistence of symptoms (n=3/20) or unusual pain in the stomach along with bleeding (n=2/20). Participants mentioned that after they had acknowledged that the symptoms were serious, they decided to see a GP:

'The bleeding got a bit more. And then I thought I got to get it checked. It shouldn't bleed all the time, it was bleeding a lot. And I thought, now is the time I should get it checked'.

Participant, 49 years, Stage 3 rectal cancer.

Abdominal pain and a change in the colour of blood (dark blood instead of the usual red colour) were cues for one participant to seek advice. One participant was not worried until the symptoms exacerbated, following which he sought advice.

6.4.3 Behavioural delay

6.4.3.1 Delay in scheduling an appointment with a GP

Most participants who had decided to seek medical advice still postponed visiting a GP for various reasons, including social and professional commitments (n=3/20), belief that symptoms did not warrant medical help (n=9/20) or belief that symptoms would resolve spontaneously (n=6/20). Two participants mentioned that they waited longer before seeking medical advice because they had lost faith in the medical system because of previous experiences with their doctor. One participant mentioned that he delayed seeing a GP because he had booked a holiday and did not want to increase anxiety while on the trip:

'We had booked a holiday in Europe in June last year. I thought well, I should go and see a doctor, but then if he found anything, I don't want to go for a holiday with a worry in my head, so I thought I'll do when I come back from my holiday'. Participant, 47 years, rectal cancer with nodal metastasis.

6.4.4 Scheduling and treatment delay

6.4.4.1 Delay in referral for a colonoscopy

Most participants mentioned that their GP performed a digital rectal examination and advised them to go for a colonoscopy based on age, symptoms and/or family history alone. However, a quarter of participants (n=5/20) mentioned that they were advised by their GP that the symptoms were benign in nature and they did not need to worry about them:

'And when I went to the doctor he sort of said "oh, it must be just haemorrhoids, and because you've been taking pain killers for your foot or whatever"'. Participant, 48 years, Stage 2 colon cancer.

One participant, who had previously undergone back surgery, consulted his back specialist about his symptoms (change in bowel habits- most commonly constipation) in a follow-up visit. He was told that the symptoms might have resulted from the pain medications he was taking. Another participant mentioned that his GP attributed the fresh blood to haemorrhoids, and he was relieved after that and did not worry about his symptoms. This participant was diagnosed with a tumour in a screening programme almost one and a half years later. The same participant acknowledged that he might have been in a better position if he had asked his GP to look further into his symptoms:

'I spoke to my GP in Queensland that time... and ... I was concerned about the symptoms at that time. I told him that I had seen some blood on my toilet paper and he said ... umm ... yeah that ... since it is fresh blood it could be piles (haemorrhoids) or something'.

Participant, 65 years, metastatic rectal cancer.

6.4.4.2 Waiting times for a colonoscopy

When men were referred urgently to a public hospital for a colonoscopy, the specialist sometimes had a long waiting list. One man who had private health insurance had a colonoscopy within two days of referral, while most of the other men without private medical insurance waited from one week to six months before having their colonoscopy. One participant mentioned that because he was going back and forth to the hospital about his symptoms, he was only taken for a colonoscopy in the fourth month.

A summary of the facilitators and barriers that affected the study participants' transition from symptom detection to a GP visit and CRC diagnosis are presented in Table 6.3.

Table 6.3: Inhibiting and facilitating factors for timely diagnosis attributable to participants

<p>Appraisal delay</p> <p><i>Impeding factors:</i> Attribution of symptoms to benign causes (bleeding—haemorrhoids, excess alcohol intake, straining during defecation; change in bowel habit—poor eating habits, excess coffee, stomach bug, hot weather or change in water or food, not drinking enough water; abdominal pain—excess alcohol intake); misinterpretation of symptoms (bleeding—lifting heavy weights; pain—past surgical history; flatulence—side effect of medications for other conditions); symptoms occurring intermittently; denial of cancer; absence of pain.</p> <p><i>Facilitating factors:</i> Persistent symptoms; aggravation of symptoms.</p>
<p>Illness delay</p> <p><i>Impeding factors:</i> Non-disclosure of symptoms to significant others (family or friends).</p> <p><i>Facilitating factors:</i> Encouragement from significant others to seek medical advice; marital status—encouragement from spouse to see the doctor; family history of bowel cancer.</p>
<p>Behavioural delay</p> <p><i>Impeding factors:</i> Failure to make time to book an appointment with the doctor; personal and social commitments; belief that symptoms would clear up naturally; adopting a wait-and-see approach; lack of awareness in the media about the occurrence of bowel cancer in younger individuals; reticence to seek medical advice in general; self-medication.</p> <p><i>Facilitating factors:</i> Worsening of symptoms.</p>
<p>Scheduling delay</p> <p><i>Impeding factors:</i> Reluctance to undergo any physical or invasive investigation; fear of diagnosis of cancer or poor prognosis.</p> <p><i>Facilitating factors:</i> Perception that the symptoms were serious; symptoms occurring more frequently; persistence of symptoms; bleeding accompanied by pain; talking about bowel symptoms during routine visit to a GP.</p>
<p>Treatment delay</p> <p><i>Impeding factors:</i> Attribution of symptoms to benign causes by a GP; delay in scheduling a colonoscopy for public patients without private health insurance.</p> <p><i>Facilitating factors:</i> Timely referral by GPs.</p>

6.5 Discussion

6.5.1 Summary of the main findings

In Study 4, the factors associated with patient and diagnostic delays for CRC among 20 men in WA were explored. Based on Pack and Gallo's ⁽²¹⁾ definition, five participants in the current study sought advice within three months of symptom onset and therefore did not delay seeking help. It has been reported that the time between the onset of symptoms and seeking medical attention can range between three and six months ^(15, 6, 22). However, about one-third of participants (6/20) in the current study delayed for more than six months, with the maximum delay being two years.

Diagnostic delays were mainly attributable to the participants and resulted from delayed action (mainly because of the failure of appraisal of symptoms) or inappropriate action by participants. The participants did not consider the symptoms serious enough to warrant medical attention and attributed the symptoms to benign conditions. Further, they were reticent to seek medical advice for other reasons, such as denial of cancer, failure to make time to arrange an appointment with a doctor or adopting a wait-and-see approach with the belief that the symptoms would resolve spontaneously. Other reasons for procrastinating to seek medical advice were fear of cancer diagnosis, self-medication and a belief that they were too young to be affected by cancer. The findings also suggested that misinterpretation of symptoms and denial of cancer led to a delayed appraisal of cancer. Further, intermittent symptoms and the absence of abdominal pain also delayed the appraisal process.

6.5.2 Comparison with previous literature

Walter et al. ⁽⁸⁾ conducted a systematic review of the application of Andersen's Model and found that only eight studies had applied the model to collect and/or analyse data for assessing cancer diagnoses. Only two of these studies explored participants' experiences with colon cancer qualitatively through in-depth interviews besides other cancers ^(2, 23). Many of the findings in the current study about patient- and system-related delays are supported by previous studies and literature reviews ^(2, 3, 5). Themes regarding influences on pre-hospital delays in the current study were similar to those found by Mitchell et al. ⁽⁹⁾ in their systematic review of 44 studies. Other reasons for delays in the current study, such as failure to appreciate symptom seriousness, denial of symptoms or fear of cancer diagnosis, are also consistent with Mitchell et al.'s ⁽⁹⁾ systematic review.

Mitchell et al. ⁽⁹⁾ observed abdominal pain and the presence of multiple symptoms as triggers to seeking advice, which is in line with the findings of the current study. In Study 4, in

addition to pain, the exacerbation of symptoms such as rectal bleeding or diarrhoea also acted as facilitators to seeking advice. Additionally, participants with a family history of cancer either sought medical advice after detecting symptoms or did not do so because of a fear of cancer diagnosis. These findings support Ramos et al.'s ⁽¹²⁾ argument that people who were familiar with CRC symptoms were more likely to seek advice than those who had witnessed cancer in their family or friends. Esteva et al. ⁽⁶⁾ observed that people with a family history of cancer had longer diagnostic interval (onset of first symptom to date of diagnosis, median duration of 138 days vs. 124.5 days, $p=0.07$) compared to those with no family history of CRC. Additionally, in line with the results of the current study, they found that symptoms such as abdominal pain shortened the delay in seeking advice. Some participants acknowledged that they delayed seeking medical advice because of a fear of being diagnosed with cancer. Such observations have been made previously in other cancer diagnostic groups—particularly breast cancer in women ^(24, 25).

As in Study 3, participants' help-seeking experience was not a linear process as described by Andersen's Model in Study 4 too. Factors such as the persistence or worsening of symptoms, or the appearance of new symptoms stimulated participants to move back and forth between the appraisal stage and the other stages of the model. This is supported by previous studies on diagnostic delays in cancer ⁽²⁾. The time taken by participants to advance from one stage of the model to another also varied among participants and was influenced by factors such as aggravation of symptoms, encouragement from a significant someone, appearance of new symptoms such as pain, and family history of bowel cancer. These findings are consistent with another qualitative study of patients' experiences of cancer symptoms and seeking advice ⁽²⁾ in which the investigators observed an overlap between different stages of the model.

According to the data obtained in the current study, several facilitators and barriers affected the delay before CRC diagnosis. Specifically, when GPs attributed non-specific symptoms to chronic conditions, and when participants misinterpreted symptoms, the delay in seeking help was prolonged. Based on the results obtained in the current study, it may be difficult to quantify the period of delay in each stage of Andersen's Model, and it may be assumed that the non-specific nature of symptoms, coupled with how they are interpreted (or misinterpreted), has a significant effect on total patient delay. This assertion is supported by a previous study ⁽²⁾ and aligns with a study by Andersen, who reported that about 60% of the total delay was caused by appraisal delay ⁽⁷⁾. Previous studies have shown that knowledge and public awareness are not adequate to facilitate a change in health-related behaviour ^(26, 27). In contrast, help-seeking behaviour encompasses multiple factors, including patients'

knowledge of symptoms and perceived cancer risk, which are in turn influenced by the healthcare system and patients' psychology⁽²⁸⁾. Diagnostic delays may also be attributed to misinterpretation of symptoms, inadequate physical examination by a GP and an overburdened tertiary healthcare system^(6, 29). This finding was also observed in the current study, where one-quarter of the participants (5/20) mentioned that they had not been investigated by their GP or that they had long scheduling periods for colonoscopy. As CRC symptoms are common in the general population and their diagnostic value for cancer is low, GPs are required to differentiate between participants with symptoms attributable to cancer and those that are attributable to benign conditions^(30, 31). Consequently, misinterpretation of symptoms by GPs may add to the delay in patients' referral to a specialist^(29, 32). Tomlinson et al.⁽³³⁾ emphasised the importance of detailed history taking and digital rectal examinations for all patients with CRC symptoms at the primary care level.

6.5.3 Implication for policy, practice and research

Study 4 supports the view that delays in CRC diagnosis are common⁽³⁴⁾. The results of this study are supported by Hashim et al.⁽²⁷⁾, who found inadequate knowledge of CRC among those at risk. The data also showed that some men believed CRC to be a disease of old age and consequently delayed seeking advice until the symptoms exacerbated. Hence, the importance of educating all men—especially those aged above 40 years—should not be underestimated. It was also observed that men who were encouraged by their spouses to seek medical advice were less likely to delay. This finding was supported by previous studies, which observed that female family members, such as wives, sisters and daughters, facilitated help seeking among men⁽¹²⁾.

In the light of this finding, health promotion campaigns aimed at promoting timely help seeking for lower bowel symptoms could emphasise the role of families in encouraging men to seek timely medical advice. The data also showed that some men discussed their symptoms with their GP during routine medical visits. Ramos et al.⁽¹²⁾ observed similar results and found that men seek medical advice during medical consultations for other reasons. Thus, it may be appropriate for GPs to play a more proactive role in questioning men in high-risk groups about lower bowel symptoms during routine medical visits. In a few cases, it was observed that GPs ruled out the possibility of cancer in patients with lower bowel symptoms. It has been recommended that GPs actively investigate patients with persistent or recurring bowel symptoms⁽³⁵⁾.

6.5.4 Strength and limitations of the study

The diversity of study participants in terms of age, social background and stage of cancer, obtained via purposive sampling, is one of the strengths of the current study because it captures the views of a wide range of the male population with CRC in WA. However, the findings of this study rely on participants' recall of events from the pre-diagnostic period. It is possible that CRC diagnosis may have biased participants' recollections. Some participants' accounts of their experiences may have been tainted by factors such as a sense of personal responsibility for any delays, thereby overestimating system-related delays^(23, 36). The recall bias may also lead to underestimation of patient delays by participants, as the experience of symptoms such as rectal bleeding may be easier to remember and recall than other non-specific symptoms⁽³⁷⁾.

Future studies could focus on the help-seeking behaviours of both men and women and apply the gender lens to explore any differences. The findings of this study were consistent with the first four stages of Andersen's Model⁽⁷⁾: appraisal, illness, behavioural and scheduling. Under the treatment delay stage of Andersen's Model, referral delays and the waiting period for a colonoscopy were the delaying factors. However, participants were not asked about any delays from colonoscopy to first treatment. Future studies could explore these factors using the expanded stage of treatment delay proposed by Walter et al.⁽⁸⁾: pre-diagnostic interval (time between first consultation with healthcare provider and cancer diagnosis) and pre-treatment interval (time between formal cancer diagnosis and initiation of treatment). Some of the themes generated in the study were more important than others as they were supported by more data. However, the themes were not classified as major themes and sub-themes in the current study.

6.6 Conclusion

The findings of Study 4 helped to explore and understand why some men in WA experience delays in CRC diagnosis. In some instances, delays resulted from men's failure to attribute their symptoms to cancer and subsequent delay in establishing a diagnosis. Delays may have been further compounded by the lack of a timely referral to a specialist and the subsequent delay in scheduling a colonoscopy. These findings may contribute to efforts to develop interventions that encourage men to seek timely medical advice leading to early CRC diagnosis. The findings also mandate further research to develop interventions to reduce diagnostic delays at the primary care level. In the next Chapter, findings from all the four studies conducted, as part of this thesis will be discussed in relation to each other and to literature. Based on the common barriers and facilitators to help seeking in each of the

studies, indicating different points along the illness trajectory, potential implications of the findings will be discussed.

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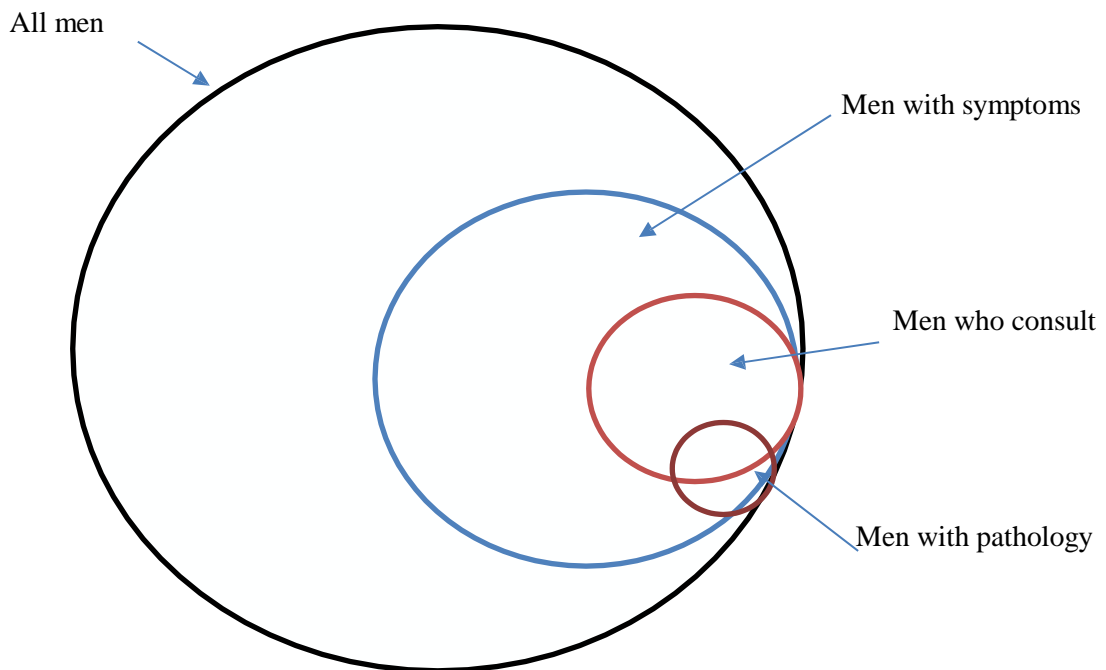
Chapter 7: General Discussion and Conclusions

7.1 Structure of the thesis

The aim of this thesis was to explore the help-seeking behaviour of men in regards to lower bowel symptoms. The aim was accomplished by determining the factors that may affect how men in the community would advise other men experiencing lower bowel symptoms (Study 1) and by explore the help-seeking behaviours of men with regards to their own lower bowel symptoms at different stages along the trajectory of disease (studies 2, 3 and 4).

A rationale for the need for timely help seeking for lower bowel symptoms was provided in Chapter 1 then a literature review conducted to explore the reasons for delay in help seeking in regards to lower bowel symptoms using a gender lens (Chapter 2). Thereafter, the thesis was structured into four separate studies (see Figure 7.1). In this section, the principal findings of four studies are discussed in relation to each other and to existing literature.

Figure 7.1: Overview of the groups of men studied in the thesis



This section provides an overview of the findings from each of the four studies, a comparison with the literature and recommendations to influence men's help-seeking behaviour.

7.2 Principal findings of the thesis

7.2.1 Study 1: video vignette survey

Study 1 explored how men would advise other men in regards to lower bowel symptoms. The results were presented as clinical, demographic and psychosocial factors that may affect men's decision making. The findings of Study 1 of the research (Chapter 3) concurred with those of a previous survey in WA by Jiwa et al. ⁽¹⁾ that found most individuals in the survey were unaware of the significance of lower bowel symptoms and would delay seeking medical advice. The same study also found that most people would seek help from a pharmacist for their lower bowel symptoms before consulting a GP ⁽¹⁾.

Men who were not tertiary educated or who had lower incomes were less likely to agree with the expert panel in regards to the vignettes warranting medical consultation. These findings were consistent with previous studies, which observed low rates of help seeking among people with a relatively lower educational or socio-economic status ⁽²⁻⁴⁾. In contrast, few previous studies have found higher socio-economic status to be a barrier to help seeking ⁽⁵⁾. Study 1 also found that participants younger than 50 years and those living in regional or remote areas were less likely to suggest the men in the vignettes scenarios should seek medical advice, even when the symptoms warranted investigation. Similar findings have been echoed by studies that highlighted younger age as a barrier to help seeking for lower bowel symptoms ⁽⁶⁻⁸⁾. These findings contrasted with those of a systematic review by Mitchell et al. ⁽⁹⁾, who found no association between the age and socio-economic status of individuals with their help-seeking behaviour however, a possible reason for this difference is that in the current research, the participants were presented with scenarios rather than experiencing the symptoms themselves.

In Study 1, participants who did not visit a GP often, or those who believed that visiting a GP was time-consuming, were less likely to recommend help seeking for vignettes warranting medical attention. Likewise, participants living in regional or remote areas were less likely to refer the men in the vignettes. In previous studies low rates of help seeking were found to be associated with people living in remote areas who have difficulty visiting a GP ⁽¹⁰⁾. This may partly be attributed to lack of knowledge about the risk associated with these symptoms or their tendency to visit a GP less often. A study on the uptake of faecal

occult blood test screening practices in a rural Queensland community found that although rectal bleeding was recognised as a symptom of CRC by most participants, very few could identify non-specific symptoms, such as change in bowel habit, abdominal pain and unintentional weight loss, as cancer symptoms ⁽¹¹⁾. Furthermore, the Australian State and Territory Health Ministers' report on the uptake of medical service among people living in regional or remote areas ⁽¹²⁾ highlighted that people living outside of urban areas were far less likely to visit a GP than those living in the metropolitan area. The report cited the relative shortage of GPs in remote areas and the higher cost of visiting a GP (as GPs in remote areas were less likely to bulk bill their patients) as reasons for not consulting a GP. This finding is particularly important, as the incidence of all cancers in Australia—especially bowel cancer and melanoma—are significantly higher, and survival rates poorer among people residing in regional areas compared with those living in major cities ⁽¹³⁾. It is also important because 1/3rd of Australian population resides in regional and remote areas ⁽¹⁴⁾. Cancer patients residing in regional and remote areas are known to experience diagnostic delays and poor survival rates ^(15, 16). A discussion paper on the equity and access of primary health care services in rural and remote Australia ⁽¹⁷⁾ further highlighted the difficulties faced by the regional and remote communities in recruiting and retaining the health work force, including the GPs and specialists and the difficulties faced by the residents in accessing healthcare services.

A recent study on the outcome inequalities of CRC in the US ⁽¹⁸⁾ found a complex relationship between non-urban dwellers and the stage of cancer at presentation and the survival period. CRC patients living in rural areas (OR 1.079; 95% CI: 1.02-1.13) and those in large metropolitan counties (population >1 million) (OR 1.036; 95% CI: 1.02-1.05) were more likely to have diminished cancer survival compared to those living in smaller metropolitan counties (population <1 million) (reference category). The survival was also lower for patients residing in counties with the lowest socio-economic index (county SES Index 1: hazard ratio (HR)=1.116; 95% CI=1.092-1.14) (county SES Index 2: HR=1.048; 95% CI=1.028-1.069) compared with counties with highest socio-economic index (reference category=county SES Index 5). The likelihood of presenting with Stage 4 cancers was also higher in counties with socio-economic index 1 (OR=1.054; 95% CI: 1.013-1.096). Additionally, men had poor health outcomes compared to women with higher likelihood to present with Stage 4 cancer (OR=1.067; 95% CI: 1.043-1.092) and poorer survival (HR=1.067; 95% CI: 1.043-1.092). The authors related these inequalities to factors such as low access to healthcare, socio-economic barriers and differing models of healthcare delivery in those areas. A similar study of the US population ⁽¹⁹⁾ found that people living in rural areas had a 15% higher risk of death due to colon cancer compared to those living in

urban areas (HR 1.15; 95% CI 1.01-1.32). Future studies could focus on the role of help-seeking behaviours in outcome inequalities among CRC patients in rural areas and in metropolitan areas with higher populations.

In Study 1 of this thesis, participants were more likely to recommend help seeking from GP for vignettes portraying men with rectal bleeding (OR=1, reference category) than for diarrhoea (OR: 0.13; 95% CI: 0.08-0.21) or weight loss (OR: 0.46; 95% CI: 0.22-0.95). In addition, the participants were more likely to recommend help seeking for vignettes portraying men with multiple symptoms occurring concurrently (OR: 1.60; 95% CI: 1.07-2.41) than those with lone symptoms and for symptoms lasting for 3 weeks compared to 3 days (OR: 3.09; 95% CI: 2.35-4.05). These findings concur with a study by Cockburn et al. ⁽²⁰⁾ on the help-seeking behaviour of adult Australian population in regards to the potential symptoms of CRC. They found that less than 50% of the population was aware of all the potential symptoms of cancer. The majority of the survey participants could only identify rectal bleeding as a symptom indicative of cancer. The findings from Study 1 were also consistent with several studies that observed a delay in seeking help among patients who attributed their symptoms to less serious conditions ^(10, 21-23) or were less likely to recognise the symptom severity ^(6, 20, 23-27). This is a cause of concern as according to the NICE guidelines for referral of suspected cancer patients to specialist care, the persistent symptoms such as rectal bleeding or diarrhoea, lasting for 4–6 weeks are indicative of bowel pathology especially among people in higher age groups (>60 years) ⁽²⁸⁾. The findings of Study 1 are also in agreement with studies reporting that most people did not consider the possibility of a life-limiting cause for their symptoms and often attributed their symptoms to benign conditions not warranting medical advice ^(2, 8, 23, 26, 27, 29).

Study 1 includes vignettes to explore how men would advise other men experiencing lower bowel symptoms. The results of studies 2–4 indicated that it is common for men to confide their symptoms in friends or family therefore it was important to know how these men would be advised by other men in regards to their symptoms using non-confrontational methods. Evidence supports vignettes as specifically useful in the non-clinical populations to study how the individuals not experiencing the symptoms would react if they were to experience the symptoms ⁽³⁰⁾. The use of quantitative methods in Study 1 facilitated the exploration of multiple factors (demographic, clinical and psychosocial) that may impact on men's decisions within a space of few minutes, with minimal potential for recall bias. Existing knowledge about the help-seeking behaviours with regards to the lower bowel symptoms is largely based on retrospective studies that rely on patients' recall of their past experiences ^(20, 31-33). These studies may be subject to information-recall bias or social desirability bias at the

time of reporting non-specific symptoms such as change in bowel habit or weight loss or embarrassing symptoms such as rectal bleeding^(20, 29). Further, if the patients are diagnosed with the life threatening illness such as cancer, the distress experienced by them as a result of diagnosis may also have an impact on the accuracy of the recall of the symptoms or their help seeking habits⁽³⁴⁾.

The use of the HBM as a theoretical framework in this study also highlighted the role of health-related beliefs with regards to help seeking. The odds of the participants recommending help seeking from viewing a vignette were much higher if the participants themselves had a higher HBM score (a score based on five domains of the HBM i.e., severity of the symptoms, susceptibility to major bowel pathology, benefits of and barriers to seeking medical advice, and the participants' confidence in their GP to help with their symptoms). More information about HBM score is provided in Chapter 3 of this thesis. Thus findings of Study 1 are consistent with existing literature that found that people were more likely to seek help if they believed their symptoms were serious and the benefits of seeking help outweighed the barriers.

7.2.2 Study 2: barriers to seeking help among men who did not seek help for their lower bowel symptoms

Study 2 included men who did not seek medical advice for their lower bowel symptoms. The reticence to seek advice for lower bowel symptoms observed in this study was concurrent with current evidence that most people experiencing lower bowel symptoms are known to not seek timely medical advice⁽³⁵⁾. The rate of seeking medical advice for lower bowel symptoms such as rectal bleeding and change in bowel habit ranges from 14 to 41% worldwide and there has not been any major change over the past two decades^(8, 36-38). Cockburn et al.⁽²⁰⁾ observed that nearly one in three Australian adults who had experienced lower bowel symptoms delayed to seek medical advice for more than three months or did not seek advice at all⁽²⁰⁾. In another Australian community-based study, Courtney et al.⁽³⁹⁾ found that nearly one in five people who experienced rectal bleeding and change in bowel habit had never sought medical advice for their symptoms. In the US, nearly 14% of the adult population experiences lower bowel symptoms that are consistent with IBS⁽⁴⁰⁾. Despite the implications for HRQoL and the significant socio-economic consequences, nearly three-quarters of patients experiencing such symptoms in the US remain undiagnosed⁽⁴⁰⁾. What is concerning is that the persistent and progressive symptoms may be associated with serious benign bowel pathology such as IBS and IBD and may significantly impair HRQoL⁽⁴¹⁻⁴³⁾, although timely help seeking may be likely to improve HRQoL in these patients⁽⁴⁴⁾.

Some studies suggested that people's decision to seek medical attention largely depend on knowledge about the significance of symptoms⁽²⁷⁾. However, based on the findings of Study 2, it is difficult to suggest that participants who were unable to interpret symptoms as serious lacked adequate knowledge about the association of symptoms with benign bowel conditions and CRC as we did not gather enough information with regards to the participants' knowledge about the cause of symptoms.

The findings from Study 2 suggested that the rationalisation and attribution of lower bowel symptoms to non-medical causes such as diet and alcohol or other miscellaneous causes such as physical or mental stress were barriers to help seeking. Other themes representing barriers to help-seeking observed were improvement in with changes in diet and life style, visiting community pharmacies for OTC medication, and not considering their symptoms serious enough to warrant medical consultation. Self-medication or the purchase of drugs OTC without a prescription may help the patients to bypass a medical consultation and save time and money. Besides, it may also prevent over-burdening of the medical system by patients presenting with trivial symptoms⁽⁴⁵⁾. Given that the lower bowel symptoms are quite prevalent in the community, OTC medication such as anti-diarrhoeal, anti-spasmodic and laxatives are commonly used by people experiencing these symptoms⁽⁴⁵⁾. However, as these drugs are intended only for short-term use, patients' reliance solely on OTC medications or pharmacists' advice for their persistent symptoms, especially in high-risk individuals may sometimes be a cause of concern⁽⁴⁶⁾. Sheen et al.⁽⁴⁵⁾ suggested that community pharmacists could be an important point of contact for patients to learn about the appropriate use of OTC medication and to seek further medical advice. Patients with persistent lower bowel symptoms and those identified to be at risk of bowel pathology can be referred to a GP by the community pharmacists. However, pharmacists may sometimes tend to under-refer patients for symptoms such as rectal bleeding or unexplained weight loss and over refer for diarrhoea⁽⁴³⁾.

Fears of invasive investigations and of a cancer diagnosis were other barriers to help seeking among men in Study 2. Public awareness campaigns may be valuable in informing people about the potential benefits of timely diagnosis and treatment of bowel conditions and may also help alleviate fears about cancer diagnosis. In contrast, the information offered in such campaigns should not be over-emphasised because it could cause harm among vulnerable patients with benign conditions by labelling them as at-risk for cancer⁽⁴⁸⁾. Health care providers in the catchment areas should be alerted of any impending campaigns to plan for expected increased demand on health services⁽⁴⁹⁾.

The time and cost associated with medical consultations and embarrassment about symptoms were also barriers to help seeking. The cost of consulting a GP in Australia has been a major topic of discussion recently with out-of-pocket expenses being higher than many other Organisation for Economic Co-operation and Development OECD countries⁽⁵⁰⁾. A report tabled by the Australian States and Territories Health Ministers in 2007⁽¹²⁾ highlighted that the cost of visiting a GP had risen over the previous few years, which led to a decline in the number of people visiting their GPs for health issues. Further, GPs willing to bulk bill their patients, bulk billing was unevenly distributed around Australia, ranging between 47% and 99%, depending on the location of the practice⁽¹²⁾. The process of bulk billing involves the GP billing Medicare directly as the patient charge for services provided by the GP equals the Medicare rebate⁽⁵¹⁾.

High out-of-pocket expense for patients visiting their GPs was proposed to be one of the reasons for decline in GP visits⁽¹²⁾. A long term report by Hopkins and Speed supports this finding⁽⁵¹⁾. A report⁽¹²⁾ highlighted that it was also harder for people, especially in regional and remote areas, to access their GPs, mainly due to population growth and a lower doctor-to-patient ratio.

Over half of Study 2 participants (8/13) believed that a GP would not be able to help with their symptoms. Some of these participants (3/13) had unsatisfactory medical experiences in the past and did not want to seek medical advice when they experienced these symptoms. One of these participants had assumed that that a GP would not be able to offer any help other than recommending dietary changes or referring them to the specialist. These findings are supported by previous research by Nooijer et al.⁽²⁷⁾, wherein, if the patient does not expect his GP to be of any major help relating, this may lead to scheduling delay. These findings are also supported by results from a previous study by Meyer et al.⁽⁵²⁾, which found that patients with established pathology were more likely to trust their GPs than the primary prevention patients.

7.2.3 Studies 3 and 4: help-seeking experiences of men who were diagnosed with benign colorectal diseases and colorectal cancer respectively

The findings from studies 3 and 4 highlighted several barriers common to help-seeking behaviours in men. These include reasons such as misinterpreting the symptoms and attributing them to dietary habit, intake of excess coffee or alcohol, or due to side effects of medications. These findings are similar to Study 2 in this thesis, wherein few men who had never sought medical advice attributed their symptoms to inappropriate dietary and (alcohol) drinking habits. It is interesting to note that regardless of diagnosis or help seeking; most

men who experienced lower bowel symptoms attributed their symptoms to dietary habits. Given that the low intake of dietary fibres, high caffeine consumption, and high lactose intake contribute to IBS symptoms ⁽⁵³⁾, and the 'Western diet' rich in fat and carbohydrate, and animal and milk proteins, in the presence of other risk factors such as smoking and obesity may trigger IBD and CRC ⁽⁵⁴⁾. Therefore, it is not surprising that participants in the current research rationalised their symptoms to dietary habits. Further, they decided not to seek medical advice when the symptoms subsided with OTC medications or changes in dietary habits, thereby reinforcing their beliefs about the diets as the main cause of their symptoms.

Some themes associated with delay in help seeking in studies 3 and 4 included the attribution of symptoms to co-existing medical conditions and also cited other non-medical reasons such as lifting heavy weights at work or prolonged physical or mental stress, and high intensity physical training as potential causes for their symptoms. These findings are not surprising, especially in the light of previous studies ⁽⁵⁵⁾ suggesting that people engaging in high stress physical activities, may abstain from seeking medical advice due to their increased tolerance to physical pain and their beliefs about such symptoms being a part of their routine physical training. This finding occurs in the backdrop of an interesting correlation between physical activity and bowel symptoms. Light and moderate physical activity has been found useful in relieving the symptoms of IBD and in lowering the risk of colon cancer by up to 50%, besides reducing the risk of GI haemorrhage, IBD and diverticulosis ^(56, 57). In contrast, high intensity physical activity may sometimes lead to a variety of GI symptoms such as cramps, bloating, diarrhoea, and GI bleeding leading to bloody diarrhoea ⁽⁵⁶⁻⁵⁸⁾. However, even in endurance athletes, the appearance of more exacerbated symptoms may be indicative of serious bowel pathology warranting medical consultation ⁽⁵⁷⁾; therefore, there is a need for more awareness about the implications of persistent symptoms among men engaged in athletic activities.

Men in these two subgroups i.e. those diagnosed with chronic or benign bowel conditions (Study 3) and with CRC (Study 4) also cited their reticence to unpleasant investigations and fear of cancer diagnosis as barriers to seeking advice for the symptoms. This finding concurs with past studies identifying similar barriers to help seeking ^(3, 20, 27). In their survey on the Australian adults help-seeking behaviour in regards to rectal bleeding, Cockburn et al. found that nearly 2% of the study population was reticent to seek help, thinking that the tests would be embarrassing or/and unpleasant ⁽²⁰⁾. One of the requirements for a good quality colonoscopy and reduced intubation times is a good bowel preparation ⁽⁵⁹⁾. However, a systematic review on anticipated behaviours for colonoscopy by McLachlan et al. ⁽⁶⁰⁾ found

laxative bowel preparation to be the most cumbersome part in the uptake of primary colonoscopy. Other barriers included a feeling of embarrassment or vulnerability, anxiety, anticipation of pain and the fear of cancer diagnosis ⁽⁶⁰⁾.

Unfortunately, most people with CRC do not present with symptoms until the cancer is at an advanced stage ⁽⁶¹⁾. As a screening test, colonoscopy has played an important role in the survival benefits of both asymptomatic and symptomatic people at high risk of cancer. It is considered to be more sensitive diagnostic tool than the radiological procedures for both benign and malignant bowel conditions ⁽⁶²⁾. Potential complications associated with colonoscopy are bleeding, perforation, and over sedation. A minority of people may be at a risk of procedural related deaths ⁽⁶²⁾. Burling et al. ⁽⁶³⁾ observed that the rate of luminal perforation associated with CT colonography in patients with symptoms of CRC, was nearly four times lower than for colonoscopy. In a study on the asymptomatic people with a higher-than-average risk of CRC, Gluecker et al. ⁽⁶⁴⁾ observed that people preferred CT colonography over both colonoscopy and the double contrast barium enema examination, as they expressed dissatisfaction and inconvenience with bowel preparation in their study. However, as colonoscopy is considered the gold standard for CRC diagnosis, it is still the most appropriate investigation for people in the high-risk bracket. Betes et al. ⁽⁶⁵⁾ suggested that a score based on gender (male), age (older) and higher BMI could be used to identify high-risk individuals for primary colonoscopy.

It is interesting to note that there were several common barriers to help seeking among men across both the groups (i.e., participants with benign or malignant bowel conditions). This suggests that not only the presence, but also the perception of the symptoms and help-seeking behaviours in regards to lower bowel symptoms among men diagnosed with benign or malignant conditions are somewhat similar in their pre-diagnostic period. Among those men who were diagnosed with cancer (Study 4), there were two distinct reasons for a delay in help seeking that were not observed in participants with benign conditions: denial of cancer (n=2/20) and a lack of awareness about the risks of cancer in younger individuals (n=1/20). This finding is in agreement with past research. In their systematic review of the studies focusing on the barriers to help seeking for symptoms of CRC, Mitchell et al. ⁽⁹⁾ found that patients' lack of symptom awareness, their misinterpretation of the symptoms and their inability to recognise the seriousness of persistent lower bowel symptoms were the major delaying factors for help seeking. These findings have been discussed in detail in Chapter 6 (Section 6.4.1.2). Other behavioural reasons for delay in help seeking were the denial of symptoms, attributing the symptoms to benign conditions, self-diagnosis and management and the lack of knowledge about cancer or about the availability of screening

programmes ⁽⁹⁾. Encouragement from family or friends (especially a female family member) with regards to seeking advice for the symptoms was a facilitator to help seeking among many participants diagnosed with benign or malignant conditions. On the other hand, non-disclosure of symptoms with significant someone also led to delay in seeking help among men diagnosed with cancer. These findings suggest the role of the family in encouraging men to seek timely medical advice. These findings are consistent with past studies ^(8, 26, 27, 66, 67) that have identified a role of patients' significant others, social networks and lay support networks (spouses, relative or friends) in encouraging them to seek medical advice for their symptoms.

One distinct reason for delay among participants who sought help (Study 3) was the help-seeking habits of other members in the family. One participant mentioned that, the fact that nobody in their family had previously sought medical advice for lower bowel symptoms deterred them from seeking help when they experienced the symptoms themselves. Another participant in the same study sought medical advice as a family norm because other members in the family sought advice if they had any symptoms. This further suggests the role of family-based culture and beliefs towards help seeking among men, and these findings may affect the potential interventions to target families as the confidants of men in order to facilitate help seeking at an opportune time. The exacerbation of the existing symptoms or the appearance of additional symptoms such as abdominal pain were facilitators to help seeking among men diagnosed with both benign and malignant bowel conditions. This is consistent with previous studies that highlight the role of exacerbation of existing symptoms, appearance of additional symptoms and pain as major drivers of help seeking ^(8, 66–69). Likewise, a family history of bowel cancer was an encouraging factor to help seeking in both groups. However, a family history of cancer acted as a barrier for few participants diagnosed with cancer and prevented them from visiting their GP in a timely manner. This suggests that a family history of bowel cancer can work both ways (i.e., facilitate or inhibit timely help seeking) and is consistent with previous studies. In their studies on help seeking, Ramos ⁽⁶⁶⁾ and Esteva ⁽⁶⁷⁾ observed that family history of cancer acted as a barrier to help seeking.

7.3 Limitations of the thesis

The limitations that are specific to the different studies conducted as part of this research are mentioned in Chapters 3–6 and need to be considered for future research. The broad limitations of this thesis are outlined below.

7.3.1 Limitations: sample and results

The findings of Study 1 of this thesis have limited generalisability to men outside of WA. Further, none of the studies conducted as part of this thesis included Aboriginal Australian men (although not specifically excluded). As Aboriginal peoples constitute nearly 4% of the WA population, it would be important in any future study to explore the help-seeking behaviours of Aboriginal men with regards to lower bowel symptoms in a culturally relevant way and also cultural barriers that may prevent indigenous people from seeking timely medical advice ^(70, 71).

The results of this research should be interpreted with caution. Study 1 (vignette survey) is a cross-sectional design study; hence the results of the regressions indicate associations between variables not causal relationships. Participants in Study 4 (those diagnosed with CRC) were interviewed post-diagnosis but before the initiation of treatment. It is possible that the participants' perspectives of their help-seeking behaviour and their recall of how they dealt with their symptoms before seeking help would be different if they were interviewed in the recovery period post-treatment. Further, as the participants in all three qualitative studies were interviewed retrospectively, there is a possibility of recall bias in their responses.

7.3.2 Limitations: trajectory

A larger epidemiological study is required to identify men at different stages of the trajectory and to investigate help seeking at different stage of the trajectory until diagnosis and treatment. A longitudinal study of a cohort of men from the onset of symptoms and follow-up to diagnosis of cancer would provide more specific information about the various factors that may affect help seeking at different stages prior to diagnosis. A longitudinal prospective study would also help to reduce the possibility of recall bias that cannot be ruled out in retrospective studies.

7.3.3 Limitations: knowledge of symptoms

Participants' knowledge of the risks associated with lower bowel symptoms was not directly measured. The help-seeking questionnaire in Study 1 did not test participants' knowledge of bowel cancer symptoms, while the interviews in studies 2–4 aimed to explore participants' help-seeking behaviours rather than directly testing their knowledge of the risks of cancer associated with the symptoms. Thus, although the results of this research may provide an insight into factors influencing help seeking, along the trajectory from the onset of symptoms to the diagnosis of cancer, it does not directly imply that a lack of knowledge of the

consequences of persistent symptoms was a major factor of delay in help seeking. In a qualitative study on the help-seeking behaviours of individuals in response to various cancer symptoms, de Nooijer et al. ⁽⁷²⁾ noticed that patients who responded to possible cancer and subsequently sought medical advice for their symptoms had sufficient knowledge of cancer to interpret the symptoms correctly. Future studies could consider collecting information on men's knowledge of the potential causes of lower bowel symptoms to assess whether a lack of knowledge is associated with suboptimal help-seeking behaviours.

7.3.4 Limitations: validation of participants' responses

Another limitation of this research was that the participants' accounts of their help-seeking experiences obtained in the qualitative studies were not validated with their family members or healthcare providers. Few participants diagnosed with cancer mentioned that there was a delay in referral to a specialist by their GP, while only a few others mentioned experiencing delays in scheduling a colonoscopy. Future research could also consider interviewing the healthcare providers in order to validate the patients' recall of their help-seeking experiences with their GP.

7.4 Use of Andersen's Model of Total Patient Delay as a theoretical framework in qualitative studies

Andersen's Model ⁽³⁴⁾ was used as a theoretical framework for data collection and data analysis across all three qualitative studies (studies 2–4). This model has been used in the past to collect information on patient delays in help seeking or total diagnostic delays. Walter et al. ⁽⁷³⁾ conducted a systematic review of the application of the model in cancer diagnosis and found it suitable for studying delays in cancer diagnosis. They also observed that most studies on diagnostic delays in cancer in the past had not applied any theoretical model to data collection and reporting. Thus, the application of a theoretical framework in each of the three qualitative studies is one of the strengths of this research.

The key finding of this research—that there are clearly identifiable stages between the detection of symptoms by patients and seeking medical advice—is consistent with Andersen's Model of delay. In a systematic review, Walter et al. ⁽⁷³⁾ found limited evidence for the differentiation of illness delay from appraisal delay. In the current research (studies 2–4) it was observed that patients often contemplated between seeking medical advice or self-treatment, as participants often bought OTC medications for their symptoms from community pharmacies and consulting other health professionals before visiting a GP. This conforms to the stage of illness delay as originally proposed by Andersen's Model.

Participants seeking OTC medication before visiting a GP also suggests that although they identified the need to seek help, some of them did not directly seek medical advice from their GP, and that the help-seeking pathway may involve other health professionals, such as community pharmacists, before the patient finally seeks medical advice. However, when approached, other health professionals may be helpful not only in offering advice and OTC medications, but also in accelerating the help-seeking process by evaluating symptoms against established screening questionnaires and referring at-risk patients to a GP⁽⁷⁴⁾. The results of the three qualitative studies (studies 2–4) also suggested that the misinterpretation and the rationalisation of the symptoms or non-recognition of symptom seriousness and attributing the symptoms to benign conditions was a major reason for delaying seeking help. This finding concurs with previous studies that observed non-recognition of symptom seriousness as a barrier to help seeking^(8, 75) and suggests that ‘appraisal delay’ stage of Andersen’s Model, which emphasises the detection of symptoms, understanding their seriousness and the risk of cancer associated with them, is a potential area for public health intervention. Most CRC patients present with symptoms at an advanced stage of bowel pathology; however, early detection and treatment has a positive effect on the quality of life post-treatment. In this context, the knowledge and awareness surrounding the potential for secondary prevention of CRC and for considerably reduced morbidity and mortality if the cancer is diagnosed at an early stage of its development could act as a motivation for help seeking.

In a systematic review, Walter et al.⁽⁷³⁾ suggested the expansion of the ‘treatment delay’ as described in Andersen’s Model into pre-diagnostic interval (time interval between first consultation with healthcare provider and cancer diagnosis) and pre-treatment interval (time between formal cancer diagnosis and initiation of treatment). However, treatment delay emerged as a prominent theme of delay in the pathway to diagnosis only in patients diagnosed with cancer (Study 4), and not in those diagnosed with benign conditions (Study 3). Further, a significant portion of delayed diagnosis was attributable to the participants (patient delay), and only a minor segment was attributable to system delay (referral or treatment delay). As the primary focus of this research was to explore patient-related delays, Andersen’s original model of total patient delay was an appropriate model. Future studies emphasising healthcare system delay as the cause of delayed cancer diagnosis may benefit by using the revised version of the model proposed by Walter et al.⁽⁷³⁾.

7.5 Implications for research and practice

The practical applications of each of the studies (studies 1–4) conducted as part of this thesis are discussed in Chapters 3–6 respectively. The overall recommendations to influence men’s help-seeking behaviours are discussed in this section. Despite the limitations discussed in Section 7.3, the findings on this thesis have several useful research and clinical implications. The findings of current research and their implications can be viewed in the context of HBM was used as a theoretical framework in Study 1 in the current thesis (Chapter 3: Section 3.3.1).

7.5.1 Findings in the context of HBM

The HBM postulates that an individuals’ perception of four variables- the *susceptibility* to the condition/outcome, the *severity* of the health condition or outcome, the *benefits* associated with recommend health action and the *barriers* to committing to the recommended health action may predict their health behaviour⁽⁷⁶⁾. The first two variables, the susceptibility and severity relate to the perception of negative health outcomes.

In regards to *susceptibility*, the model states that people will not be inclined to prevent a negative health outcome that is unlikely to adversely affect them⁽⁷⁷⁾. Second, people will be more motivated to avoid a negative health-related outcome if they believe the outcome will be severe⁽⁷⁶⁾. In other words, unless the anticipated health outcome will have immense impact on people’s HRQoL such as mental or physical impairment, pain, or bear more severe outcomes such as death, they are not very likely to act on their symptoms or take preventive health action⁽⁷⁷⁾. The results of this research relate to these two variables of the HBM. The results of Study 1 (vignette survey) suggested that the duration of symptoms and the nature of symptoms impacted on whether the participants recommended vignettes for help seeking. Participants were less likely to refer to vignettes for help seeking unless all the three symptoms presented in the vignettes (rectal bleeding, diarrhoea and weight loss) occurred concurrently. They were also less likely to recommend help seeking for men experiencing diarrhoea and weight loss than for rectal bleeding. The findings suggest that the risk of bowel pathology- whether chronic bowel diseases or the benign/ malignant bowel pathology associated with persistent symptoms, occurring alone or concurrently, needs to be emphasised in health information campaigns. Further research on the utility of educational campaigns aimed at increasing awareness about the seriousness of the symptoms and in facilitating help seeking is warranted. Currently, there is mixed evidence on the translation of increased knowledge about the symptoms of CRC into timely help seeking for early diagnosis of cancer. Sheikh et al.⁽⁷⁸⁾ reported a weak positive correlation between knowledge

and help seeking among the British population. The authors also suggested that people's beliefs about cancer may account for the gap between knowledge of symptoms and timely help seeking. Findings from another English study by McCaffery et al. ⁽⁷⁹⁾ found that the poor knowledge about CRC was directly related to negative attitudes to the disease. The authors also emphasised the need to improve knowledge about CRC among all population groups to improve cancer-related outcomes. These findings suggest that increasing people's knowledge about the CRC and cancer warning signs may reduce negative perceptions surrounding the disease, although they do not imply that improved knowledge will facilitate timely help seeking or participation in screening programmes.

Conversely, some studies have presented a contrasting view on the effect of knowledge on health outcomes. Crosland et al. ⁽⁸⁾ found no difference in knowledge of the potential causes of rectal bleeding among consulters and non-consulters. Likewise, Hashim et al. ⁽⁸⁰⁾ observed no association between the knowledge of CRC symptoms and the delay in seeking medical advice in the Malaysian population. Similar findings were observed by Cockburn et al. ⁽²⁰⁾ in the Australian population, who suggested that the media campaigns aimed at improving people's knowledge about the risks of cancer had not been successful in influencing people to seek timely medical advice. They also advocated for the need for more intensive public education campaigns focused on addressing perceptions about cancer and the knowledge deficit surrounding the risks of cancer associated with lower bowel symptoms ⁽²⁰⁾. The current study did not directly test participants' knowledge about the risk of cancer linked with persistent symptoms which is one of the limitations. Therefore, based on the results of the current research, it is difficult to suggest whether an increase in knowledge of the long-term implications of the symptoms would improve help-seeking behaviour. It also needs to be evaluated whether information about the high rate of curability of cancer with early diagnosis disseminated through the public health media campaigns will affect the fear associated with cancer diagnosis and increase the motivation for timely help seeking. Currently, there are specific guidelines for the referral of patients with lower bowel symptoms and who are at risk of CRC to specialist care ⁽²⁸⁾ are at risk of CRC to specialist care. However, there is a need for guidelines in regards to how soon after the onset of lower bowel symptoms the first medical advice ought to be sought.

Unlike the *severity* and *susceptibility* which relate to the negative perceptions of the anticipated health outcome, the other two variables of HBM, the *benefits* and *barriers* concern people's perception of the recommend health action or target health behaviour ⁽⁷⁷⁾. For instance, if people believe that the target behaviour or preventive health action would mitigate the health risks associated with the symptoms, they would have a higher motivation

to pursue the recommended health behaviour⁽⁷⁶⁾. On the other hand, if people perceive major barriers in the uptake of preventive health actions such as accessibility of health services, embarrassment, pain, they would be less likely to perform target behaviours⁽⁷⁶⁾. In the context of present research, the ability to seek timely help may be subject to men's socio-economic background, and the availability of resources to visit a GP. This implies that if it is difficult for men to seek medical advice it is going to be perceived as difficult for these men to seek timely medical advice regardless of the knowledge and information about the possible implication of persistent symptoms. Such reason may include but are not limited to lack of time due to other (professional or social) commitments, cannot afford to pay the GP fee, living in a regional or remote area with nil to few primary care providers nearby and /or there are long waiting periods to consult a GP. Other reasons might include their embarrassment to discuss their symptoms with the GP or their reticence for invasive procedures such as colonoscopy. In Study 1, men living in regional and remote areas were less inclined to refer the vignettes for help seeking. It is important to understand the barriers to help seeking among men living in rural and remote areas to facilitate timely help seeking among such individuals. There is evidence from past research suggesting that limited access to health services in rural and remote areas may slow down the diagnosis of cancer⁽⁷¹⁾. Travelling to metropolitan/larger cities in Australia may impose financial stress on individuals such as loss of income and travelling- and accommodation-related expenses. This, coupled with prolonged waiting times for making an appointment with a GP in rural and remote areas, may lead to delayed help seeking by people living in such areas⁽⁷¹⁾. These findings also resonate with the results of other international studies, which have found the late presentation of symptoms by rural inhabitants, with their health beliefs and socio-economic factors being major barriers to the early diagnosis of cancer⁽⁸¹⁻⁸³⁾.

Past research has found that men in rural areas are less likely to relate their lower bowel symptoms such as rectal bleeding, change in bowel habit and abdominal pain with CRC. They are also less motivated for preventive health check-ups compared to women⁽¹¹⁾. Further, the concentration of colonoscopy services to larger cities and the time and cost associated with travelling may further discourage people from seeking help at an opportune time⁽¹¹⁾. Distance from the healthcare services may act as a barrier to screening and is associated with late-stage diagnosis of CRC^(84, 85); therefore, the provision of basic medical services is imperative to the early diagnosis of cancer. Burman et al.⁽⁸⁶⁾ found that rural dwellers had serious concerns about the different aspects of cancer diagnosis and treatment, such as physical symptoms, pain, body image issues, poor quality of life, financial expenses and separation from family and friends. The solutions to some of these problems may lie in tele-health services, which offer an opportunity for reduced time to initiation of treatment,

increased ease of access to medical care and reduced healthcare costs for patients⁽⁸⁷⁾. Jiwa et al.⁽⁸⁸⁾ suggested that telephone-based consultations and prescriptions for patients seeking same-day appointments were a viable alternative to face-to-face consultations and resulted in high patient satisfaction. Easier and timely access to medical services in regional and remote areas may make it easier for people living in such areas to seek help at an opportune time. Such measures have also been recommended in the past⁽⁷¹⁾. Further research is warranted regarding how these concerns affect the help-seeking behaviours of men living in rural areas for lower bowel symptoms.

The re-orientation of health services, which is an important component of the Ottawa Charter for Health Promotion⁽⁸⁹⁾, may facilitate help seeking in a timely manner. In the current research, a number of participants recommended health advice for symptoms presented in the vignettes (Study 1) and in the qualitative studies (studies 2–4) be sought from other health professionals, such as pharmacists. This suggests scope for introducing health promotion interventions in the community pharmacy setting. However, this suggestion must be considered with caution, as pharmacists' decisions to refer the patient to a GP may be influenced by a number of factors, predominantly by the nature of symptoms. People experiencing any symptoms are required to consult a pharmacy staff as per the WA law before they can purchase an OTC drug for diarrhoea or rectal bleeding⁽⁹⁰⁾. Through this process the community pharmacists may be able to identify men with significant bowel pathology requiring further investigations and also advise them to seek medical advice from their GP. Past research supports the use of self-administered questionnaires used by GPs and community pharmacists to screen the high-risk cases of bowel pathology^(52–56). While, the Patient Consultation Questionnaire⁽⁹¹⁾ and the bowel symptoms questionnaire developed by the CRISP Study⁽⁹²⁾ are useful to triage high-risk patients for bowel pathology to specialist services, the JLT⁽⁵²⁾ offers the opportunity to identify patients with high risk of bowel pathology in community pharmacies through self-administered questionnaires. Jiwa et al.^(70, 93) suggested that most of the individuals seeking help from community pharmacies would present with relatively less serious symptoms would still be treated within the pharmacy setting; however, those that are identified as being at risk of serious bowel pathology should be referred to a GP. They also suggested that majority of the patients, who were advised to seek medical advice by the pharmacists would consult the doctor. In their vignette-based study on the referral patterns of pharmacists for patients experiencing lower bowel symptoms, Jiwa et al.⁽⁴⁷⁾ observed that the pharmacists over referred patients with diarrhoea while those with unintentional weight loss were under referred. The pharmacists also failed to refer some cases of rectal bleeding meriting medical consultation for further investigation. Therefore, one possible barrier in the pharmacists' role in screening and advising high-risk

individuals to seek medical advice could be their own knowledge of the high-risk case scenarios and about the referral guidelines.

Delay in seeking help from GP, long waiting lists for investigations in public hospitals, as mentioned by some of the participants diagnosed with CRC in this research (Study 4), as well as the long distances and travel time to the specialist medical centre from regional or remote areas ⁽⁷¹⁾, may act as barriers to help seeking. The re-orientation of health services to involve other health practitioners as providers of care and the use of tele-health services may make it easier for individuals to seek help at an opportune time and thus facilitate timely diagnosis of bowel disorders. In their study on the nurse-practitioner-led remote sigmoidoscopy in a community setting in the UK, Wan et al. ⁽⁹⁴⁾ observed that all patients with rectal bleeding were satisfied with the process. The study reported that more than two-thirds of patients presenting with rectal bleeding had minor anorectal issues that could be investigated and treated in the community ⁽⁹⁴⁾. Due to the need for physical examination followed by colonoscopy in symptomatic individuals at risk of CRC, the tele-health services alone may not be very useful in establishing the diagnosis. However, people experiencing lower bowel symptoms in the pre-diagnostic phase may have a number of information and emotional needs. The use of tele-health services in meeting these needs of individuals in the lead up to diagnosis of cancer may be explored ⁽⁹⁵⁾. Past research provides evidence for the increase in screening uptake for CRC through the use of tele-health services in the US and Canada ⁽⁹⁶⁻⁹⁸⁾. The use of tele-health in encouraging high-risk individuals to seek medical advice from a GP in person may be explored in future research.

Some of the findings in this thesis can also be viewed in the context of *cue to action*, another domain of HBM. The model states that individuals may be urged to adopt a preventive health action or the recommended health behaviour by external cues such as mass media campaigns or advice from their social network of family and friends or internal cues such as deteriorating health condition ⁽⁷⁶⁾. The data from the current research showed that family members—especially spouses and mothers—could be an effective trigger for men to seek help. As discussed in the respective chapters, in studies 3 and 4 on the thesis some participants diagnosed with benign and malignant colorectal conditions respectively) who had discussed their symptoms within their lay network (family and friends) were encouraged to seek medical advice, especially by their spouses. In both of these studies, men were likely to seek help without much further delay when their family, especially their female partners, sanctioned the help seeking. This is consistent with past research findings, which have suggested the sanctioning of help seeking by others as a strong mediator to help seeking ^(75, 99). Other family members, such as their mother, also encouraged a few participants to seek

help. This finding is also supported by past research ⁽⁶⁶⁾ emphasising that close relatives—especially women—can trigger help seeking, especially among men.

The integration of peer relationships, such as family and friends, for facilitating help seeking, especially cancer screening and prevention, as well as the role of peers in providing appraisal support is of immense significance with regards to health promotion ⁽¹⁰⁰⁾. There is evidence that people, especially men who are married or who have a higher level of social support, are more likely to seek help for their symptoms or engage in preventive health programmes. Women in particular have been found to play a major role in encouraging their male partners to seek timely medical advice for their symptoms ⁽¹⁰¹⁾. Crosland et al. ⁽⁸⁾ found that regardless of help seeking, most people discussed their rectal bleeding with friends or relatives—most commonly their spouse. In regards to the participants diagnosed with cancer (Study 4), many were accompanied by their family members (in most cases their spouses) at the time of the interview. In some cases, the spouses helped the participants in their recall of information regarding their previous experiences of the symptoms and of help seeking. This further suggests that men often discuss their symptoms with their spouses, and the latter can play an important role in motivating men to seek timely medical advice for their symptoms. A study conducted in a rural Queensland community ⁽¹¹⁾ found that women were more knowledgeable than men in regards to the warning signs and symptoms for CRC, and they were more willing to participate in preventive health check-ups. It was also found that in many cases, men who went for FOBT were encouraged by their wives. This further highlights the role of women in encouraging men to seek medical advice for their symptoms.

Future research may also consider interviewing the accompanying partners or family members to get a better understanding for men's reasons for delaying help seeking. Similar views were echoed in a study by Jiwa et al. ⁽⁷¹⁾, who emphasised the role of relationships and informal networks in facilitating the early diagnosis of cancers that rely on the recognition of symptoms and help seeking. Knowledge of a family member diagnosed with CRC acted as a trigger for some participants in Study 4 (men diagnosed with CRC) to seek help for their lower bowel symptoms. However, the family's role in triggering men to seek help must not be over-played and must be emphasised only in cases of persistent symptoms. This is because it may create anxiety for minor symptoms that may not warrant medical consultation, and it may over-burden the primary care system ⁽⁴⁸⁾. In a meta-analysis of the effectiveness of the four main HBM variables (severity, susceptibility, benefits and barriers) in predicting health behaviour, Carpenter ⁽⁷⁷⁾ observed that benefits and *barriers* emerged as the strongest predictors. On the other hand, *severity* was a weak predictor of behaviour and *susceptibility* was almost always unrelated to the behaviour. The meta-analysis reported

susceptibility as a weak predictor of recommended health action in studies related to preventive behaviours as well as those related to treatment-seeking behaviours.

7.6 Conclusions and recommendations

This thesis explored the help-seeking behaviour of men in regards to lower bowel symptoms. There were four studies conducted as part of this research with each study guided by a theoretical framework.

7.6.1 Study 1 conclusions

Study 1 (Chapter 3) was a web-based cross-sectional survey of men in regards to how they would advise other men for their lower bowel symptoms. The survey used video vignettes as a tool for data collection. The three main outcomes of the survey were (a) should the person in the vignette seek health advice for his symptoms? (b) Who should he seek advice from? (c) How soon should he seek advice? The participants' responses were benchmarked by the responses from expert panel.

Study 1 was an appropriately powered survey with a sample of men (N=408) from the general population (response rate 51%), with each participant answering eight randomly selected vignettes resulting in a total of 3264 observations (408x8). The results were summarised as various factors – demographic, clinical and psychosocial associated with the study outcomes and were presented as Odds ratios, *p* value and 95% CI.

The findings suggested that a considerable proportion of men would not advise other men, even if they were experiencing multiple lower bowel symptoms, to seek help from a GP. Some factors associated with the low rate of referring vignettes for help seeking identified in this study were respondents' lower socio-economic status, living in regional or remote areas compared to metropolitan areas, and the time associated with visiting a GP.

The results of the survey demonstrated that men younger than 50 years, those with lower socio-economic status had lower odds of agreeing with the expert panel in regards to which vignettes should be referred to GP. Participants residing in regional or remote areas or those visiting their GP less frequently were also at lower odds of agreeing with the expert panel. Furthermore, vignettes portraying symptoms such as unexplained weight loss and diarrhoea were at lower odds of being referred to GP compared to rectal bleeding. As it was a cross-sectional survey, the results of GEE models do not imply causation.

The HBM was an applicable model to study men's help-seeking behaviour in this study, and the HBM score, which was used as a measurement of men's health beliefs regarding the

lower bowel symptoms, was directly related to the odds of recommending seeking help. The study also demonstrated that it was feasible to collect a large amount of sensitive health-related information from men through the use of internet and video vignettes.

7.6.2 Study 1 recommendations

In Study 1 men's decision to advise other men about their lower bowel symptoms in agreement with the expert panel, were associated with their demographic characteristics and the clinical symptoms presented in the vignettes. Additionally, a number of participants in this study suggested seeking health advice from health care professionals such as pharmacists. The role of education and age in help seeking needs to be further explored in a larger community-based setting. Any variations in help-seeking behaviours among men in different age groups and with different social and educational backgrounds may be important in the design and development of potential interventions to facilitate timely help seeking among men.

Therefore, the recommendations from this study are:

1. Campaigns or initiatives focusing on the importance of early presentation of persistent lower bowel symptoms should be specifically target men younger than 50 years, those with lower incomes and those residing in regional or remote areas.
2. Men should be educated about the clinical implications of persistent lower bowel symptoms such as change in bowel habit or unexplained weight loss in regards to bowel pathology.
3. Community pharmacists could play a role in educating men about the risks associated with persistent lower bowel symptoms and could advise them to seek help from a GP if warranted thereby supplementing their role as health promotion agents.
4. Steps should be taken to improve access to consultation and diagnostic services in regional and remote areas. The use of tele-health services (as discussed in Section 7.5.1) may facilitate easier access to GPs and specialists for individuals in regional and remote areas to seek advice about their symptoms at an opportune time and thus facilitate timely diagnosis of bowel disorders in individuals requiring intervention.
5. Findings of this study such as the associations of low socio-economic status, age, living in regional or remote areas with help seeking should be confirmed in future research through longitudinal study.

7.6.3 Study 2 conclusions

In **Study 2** (Chapter 4), semi-structured qualitative interviews were conducted with men from the community, who experienced lower bowel symptoms but did not seek medical advice. The data collection and analysis in this study was guided by Andersen's Model of Patient Delay. Data saturation was obtained (N=13) and thematic analysis was used to identify the themes reflecting the barriers to help seeking.

Some of the barriers to help seeking were failure to interpret the severity of the symptoms, rationalising the symptoms, intermittent nature of the symptoms, self-management of symptoms with OTC medications or with changes in dietary habits, and the fear of cancer diagnosis. Reticence for investigations, cost of visiting the GP and men's confidence in medical consultation were other barriers to help seeking. Some men did not discuss their symptoms with their family members out of embarrassment.

7.6.4 Study 2 recommendations

In **Study 2**, attribution of lower bowel symptoms to common causes such as haemorrhoids, inappropriate dietary habits, alcohol, and stress were common themes. Furthermore, many participants did not seek medical advice as they decided to self-manage their symptoms through OTC medications. However, participants' knowledge about the causes of the symptoms and risk associated with these symptoms could not be established. Knowledge about the symptoms is pertinent to correct interpretation of the symptoms.

Therefore, the recommendations from this study are:

1. Future research should test the association between men's knowledge about the potential causes of their symptoms and their help-seeking behaviour.
2. As men are likely to visit a community pharmacy at some point during the course of their symptoms, community pharmacists could play a role in identifying clients purchasing products that indicate lower bowel symptoms and also advise individuals to referral to GP is indicative.
3. Health awareness campaigns about lower bowel symptoms and associated bowel pathologies may help to alleviate fears about investigation and cancer diagnosis and encourage people to visit their GP when symptoms first occur.

7.6.5 Study 3 conclusions

In **Study 3** (Chapter 5), semi-structured qualitative interviews were conducted with men diagnosed with chronic bowel conditions or benign bowel pathology from the hospital setting. Similar to Study 2, the data collection and analysis in this study was also guided by Andersen's Model. Data saturation was obtained (N=19) and thematic analysis was used to identify the themes reflecting the barriers and the facilitators to help seeking.

The study provided evidence of delayed presentation of lower bowel symptoms by men diagnosed with chronic or benign conditions and reasons for delay. The various barriers and facilitators to help seeking were categorised into the five stages of Andersen's Model. The greater proportion of participants in this study reported delay in seeking help rather than any system delay in the pathway to diagnoses. The study found that this 'appraisal delay' stage of delay in Andersen's Model contributed the most to the total delay in seeking medical advice and establishing a diagnosis because of a lack of knowledge about the symptoms and misinterpretation of the symptoms. The common barriers were misinterpretation of symptoms, attribution of symptoms to common causes, and failure to arrange time to visit a GP. Other themes reflecting barriers to help seeking were fear of cancer diagnosis and embarrassment associated with the symptoms. The factors that facilitated help seeking were the exacerbation of symptoms, disclosure of symptoms to a confidant and encouragement to consult a GP by a female family member.

7.6.6 Study 3 recommendations

Therefore, the recommendations from Study 3 are:

1. Appraisal delay is a significant area for potential interventions to encourage timely help seeking among men. Public health campaigns should focus on education and awareness about diminished quality of life, risk of absence from work, loss of productivity and risk of CRC associated with persistent lower bowel symptoms. The information should also be communicated through channels that are more likely to facilitate help seeking such as family, spouses and friends.
2. Community pharmacists can play a role in referring men with early stage through to persistent lower bowel symptoms to GP for timely medical advice, who can then facilitate timely specialist referral if needed.

3. Interventions targeting men for timely help seeking about their lower bowel symptoms should also involve family members (particularly partners) and friends who are confidants.

7.6.7 Study 4 conclusions

Study 4 (Chapter 6) was the final study in this thesis and aimed to explore the barriers and facilitators to help seeking among men diagnosed with CRC. Like studies 2 and 3, Study 4 also used qualitative semi-structured interviews to explore men's help-seeking behaviour in regards to their lower bowel symptoms. Data saturation was achieved with a sample of men recruited from the Hospital setting (N=20). As in studies 2 and 3, the data collection and analysis was guided by Andersen's Model.

The barriers to seeking timely medical advice were mainly attributed to the misinterpretation of symptoms, fear of cancer diagnosis, reticence to discuss symptoms or consult a GP. 'Patient-related' delays were more common than delays attributable to the healthcare system. In many instances, delays resulted from men's failure to attribute their symptoms to cancer and subsequently delayed their diagnosis. Data regarding patient delays fit within the first four stages of Andersen's Model. Treatment delays were a minor cause for delayed diagnosis and delays in referral and scheduling for a colonoscopy were among the system delay factors. Nearly 1/3rd of the participants in this study delayed for more than six months to seek help from their GP, with maximum delay being two years. The reasons for delay were quite similar to those observed in studies 2 and 3 and included misinterpretation of symptoms, the 'wait-and-watch approach' and belief that the symptoms would clear up spontaneously. Denial of cancer, failure to make time to visit a GP, fear of poor prognosis, and a belief that they were too young to be affected by cancer were other themes that reflected barriers to help seeking. Absence of abdominal pain was also cited as a reason for delay. These findings corroborate with studies 2 and 3 in this thesis as well as existing literature. Most men who sought advice were encouraged by spouses or other female family members.

7.6.8 Study 4 recommendations

1. Public health education campaigns should target all men - especially those above 40 years to increase awareness about the potential causes of persistent symptoms and the risks associated with late presentation to GPs.

2. Interventions targeting men's help-seeking behaviour should consider involving family members, or partners or friends to encourage men to seek timely medical help.
3. This study found some delay by GPs in referring men to secondary care after their first medical visit. (The current study did not interview family members or GPs to validate the information provided by men.) Future studies should consider involving family members and GPs to obtain greater insights into men's help-seeking behaviour.
4. GPs should be encouraged to be more proactive in questioning men about their bowel habits and other lower bowel symptoms during men's routine visits.

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Appendices

Appendix 1.1: Gender differences related to incidence and risk of developing CRC as reported in Chapter 1

Table A1.1 Gender differences related to incidence and risk of developing CRC as reported in Chapter 1

	Males	Females
Incidence ASR (W) * in the following countries		
World	20.3	14.6
USA	34.1	25.0
UK	37.3	25.3
Australia	46.0	32.1
Europe	37.4	23.9
Risk of developing		
Polyps	OR 1.5	OR 1.0 (Ref)
Carcinoma	OR 1.4	OR 1.0 (Ref)
Advanced neoplasia (after adjusting for colonoscopic factors, age and family history)	OR 1.98	OR 1.0 (Ref)

*ASR (W): Age-standardised rate per 100,000

References: [68, 70] (Chapter 1)

Appendix 1.2: Gender differences related to prognosis and mortality from CRC

Table A1.2: Gender differences related to prognosis and mortality from CRC

	Males	Females
Prognosis		
5 year survival rate	63.7%	63.5%
Overall survival after resection [Mean(SD)]	52.0 (1.3) months	57.8 (1.5) months
Disease free survival after resection [Mean(SD)]	46.0 (1.4) months	51.6 (1.7) months
Hazard ratio (adjusted for age, site, presentation and Duke's stage)	1 (ref)	0.76
Mortality ASR (W) * in the following countries		
World	9.6	7.0
USA	9.9	7.7
UK	13.9	9.1
Australia	15.9	9.5
Europe	17.0	10.6

*ASR (W): Age-standardised rate per 100,000

References: [36, 68, 70, 71, 74] (Chapter 1)

Appendix 2.1: Studies included in this review as reported in the literature review section in Chapter 2

Table A2.1: Studies included in this review as reported in the literature review section in Chapter 2

SI no.	Authors	Location	Study type	Cancer site	Length of delay	Sample size	Definition of delay	Factors increasing delay	Factors decreasing delay	Gender associated with longer delay
1	Vinesis (1993)	Italy	Retrospective (interview + hospital records)	Colon	22 days (mean)	97	Until diagnosis	Low educational status	Not specified	Not specified
2	Kemppainen (1993)	Finland	Retrospective (hospital records)	Colorectal	82.8 days (mean)	101	Until seeking help	Younger age in men and older age in women	Not specified	Male (<65 years), Female (>80 years)
3	Curless (1994)	UK	Prospective, observational	Colorectal	19.5 weeks (median)	273	Until diagnosis	Attribution to benign causes, non-recognition of symptom seriousness	Not specified	Not specified
4	Stebbing (1995)	UK	Retrospective (hospital-based)	Colon	61 days (mean)	89	Until diagnosis	Patients' ignorance of the symptoms, fear of diagnosis and unpleasant investigations or treatment	Not specified	Not specified
5	Crosland and Jones (1995)	UK	Retrospective	Rectal bleeding	2 months (median)	518	Until seeking advice	Age 40–60 years, not serious, self-treatment, symptoms cleared, embarrassment, attribution to benign causes	Age >60 years, blood mixed with stool, perceiving symptoms as serious, worry about serious disease, pain or discomfort, opportunity during consultation for other reasons, embarrassment, pressure from relatives	Not specified
6	Arbman (1996)	Sweden	Prospective, observational	Colon, rectum	1 month	554	Until diagnosis	Cancer site: rectum	Presentation of symptoms as emergency	Not specified

SI no.	Authors	Location	Study type	Cancer site	Length of delay	Sample size	Definition of delay	Factors increasing delay	Factors decreasing delay	Gender associated with longer delay
7	Porta (1996)	Spain	Prospective, observational	Colon, rectum	<1 month to >3 months	183		Older age, low educational status, lower SES, unemployment, non-recognition of symptom seriousness	Comorbidity	Male
8	Mulcahy (1997)	Ireland	Prospective (hospital-based)	Colorectal	3.88 months (mean)	777	Until treatment	Cancer site: rectum	Intestinal obstruction, older age, late-stage tumour	None
9	Hansen (1997)	Denmark	Retrospective	Colorectal	3 months	50	Until diagnosis	Not considering cancer as a cause for their symptoms, fear of surgery	Accompanied by diarrhoea, being employed, past history of abdominal or bowel surgery, non-smoker	Not specified
10	Majumdar (1999)	USA	Retrospective (hospital and office records)	Colorectal	14 weeks	194	Until diagnosis	Weight loss	Intestinal obstruction	None
11	Roncoroni (1999)	Italy	Prospective, observational (hospital-based)	Colorectal	10.8 weeks (mean)	100	Until treatment	Symptoms not considered as being serious, attributing symptoms to benign conditions, changes in diet and lifestyle, fear of cancer	Influence of relatives	Not specified
12	Young (2000)	Australia	Retrospective	Colorectal	3 months	100	Until treatment	Non-recognition of symptom severity, lack of concern about the symptoms, attributing symptoms to benign causes, refusal of investigations	Not specified	Male
13	de Nooijer (2001)	Netherlands	Qualitative	Colon	Few hours to 10 months	(n=6, colon cancer)	Until diagnosis	Non-recognition of non-specific symptoms as cancer symptoms and their severity, attributing symptoms to benign causes, denial of cancer, fear; cancer site: colon	Trust in GP, fear, knowledge of symptoms, consulting someone significant about the symptoms	Not specified

Sl no.	Authors	Location	Study type	Cancer site	Length of delay	Sample size	Definition of delay	Factors increasing delay	Factors decreasing delay	Gender associated with longer delay
14	Mariscal (2001)	Spain	Cohort (hospital-based)	Large bowel cancer	59 days (median), 98 days (mean)	158	Until diagnosis	None	Comorbidity, symptoms with rectal bleeding, pain	None
15	Bain (2002)	Scotland	Qualitative (interviews and focus groups)	Colorectal	Not specified	95	Until treatment	Rural area, transportation, symptom denial, deferred appointments, difficulty in visiting a GP, fear of bad news and test results, belief that symptoms were not serious to warrant medical attention	Not specified	Not specified
16	Kiran and Glass (2002)	UK	Retrospective, observational	Colorectal	<6 months to >6 months	232	Until treatment	Living alone	Not specified	Not specified
17	Cockburn (2003)	Australia	Retrospective	Colorectal	Up to 3 months (65.3%), >3 months (2.7%), never sought advice (31.9%)	1332	Until seeking advice	Non-recognition of severity of symptoms, attribution to benign causes, symptoms resolved spontaneously, unpleasant and embarrassing tests	Not living with partner, retired from job	None
18	Langenbach (2003)	Germany	Prospective, observational	Colon and rectum	Mean: 93 days (colon), 157 days (rectum)	70 (40 colon cancer and 30 rectal cancer)	Until seeking advice	Fear of unpleasant investigation, hope for spontaneous resolution, symptom denial, low income, not living with spouse/partner (rectal cancer)	Married, symptom knowledge and awareness of risk factors	None
19	Broughton (2004)	UK	Qualitative (interview)	Colorectal	1 week to 1 month	49	Until diagnosis	Attribution of symptoms to benign causes, belief that symptoms would resolve spontaneously, intermittent symptoms, ignorant of the symptoms (rectal bleeding and change in bowel habit)	Severe and unusual symptoms (rectal bleeding and persistent change in bowel habit), social group influence	Not specified

Sl no.	Authors	Location	Study type	Cancer site	Length of delay	Sample size	Definition of delay	Factors increasing delay	Factors decreasing delay	Gender associated with longer delay
20	Robertson (2004)	UK	Retrospective (medical records)	Colorectal	138 days (mean)	1071	Until treatment	Age <50 years, non-specific symptoms, past history of anxiety, depression or benign bowel disease	Younger age group (50–64 years), increasing number of symptoms, site of cancer (transverse colon and splenic flexure)	Not specified
21	Khattak (2005)	UK	Prospective	Colorectal	30 days (median)	101	Until seeking advice	Low socio-economic status, poor awareness of symptoms, suboptimal primary care facilities	Severe and worsening symptoms, unusual symptoms	Not specified
22	Ristevdt (2005)	USA	Retrospective	Rectal	14 weeks	120	Until diagnosis	Lack of knowledge, denial or uncertainty of symptoms being due to cancer, non-recognition severity, attributable to haemorrhoids and other benign medical conditions, changes in diet, physical injury or stress	Not specified	Not specified
23	Korsgaard (2006)	Denmark	Prospective, observational	Colorectal	150 days (colon), <60 days (rectum)	733	Until treatment	Vague and non-specific symptoms (colon)	Monosymptomatic rectal bleeding (CRC)	Not specified
24	Lynch (2007)	Australia	Cross-sectional	Colorectal	<1 week to >2 months	1467	Until seeking advice	Lack of health insurance (not significant)	Abdominal pain, older age; cancer site: rectum	None
25	Hansen (2008)	Denmark	Cohort	Colorectal	21 days (median)	254	Until diagnosis	High socio-economic status	Older age, retired (females only), non-smokers (females only), higher education, higher SES	None

SI no.	Authors	Location	Study type	Cancer site	Length of delay	Sample size	Definition of delay	Factors increasing delay	Factors decreasing delay	Gender associated with longer delay
26	Ristvedt and Trinkaus (2008)	USA	Retrospective	Rectal	Females: 9–15 weeks (median) Males: 2.5–13 weeks (median)	62	Symptom appraisal	Non-recognition of the seriousness of the symptoms (due to low anxiety levels)	Not specified	Males delay more than females to appraise their symptoms
27	Ramos (2010)	Spain	Qualitative (interview)	Colorectal		12	Until diagnosis	Family history of cancer, lack of knowledge about CRC, waiting time for colonoscopy	Changes in symptoms, persistence of symptoms, social support from a female member of the family, fear of cancer, bright red blood in stools, symptom disclosure	Male
28	Courtney ^a (2012)	Australia	Cross-sectional	Lower bowel symptoms	2 weeks (RB) and 4 weeks (CIBH*) to never consulted a GP	1117	Seeking advice	RB*: no screening advice from doctor, no private health insurance, belief that symptoms were not serious CIBH: higher income, high BMI	RB: believed the symptoms were serious CIBH: symptoms did not go away, family history of CRC was discussed with doctor	RB: male
29	Tomlinson (2012)	Canada	Cross-sectional	CRC	<1 month (n=43), >1 month (n=44)	87	Seeking advice	Symptoms not considered serious, smaller size stool, constitutional symptoms, use of OTC medications	Cancer sites: cecum, rectum	Male

SI no.	Authors	Location	Study type	Cancer site	Length of delay	Sample size	Definition of delay	Factors increasing delay	Factors decreasing delay	Gender associated with longer delay
30	Courtney ^b (2012)	Australia	Retrospective	CRC	1 week to never sought advice	1117	Until seeking advice	Did not consider the symptoms serious, symptoms cleared itself, symptoms attributed to benign conditions, wait-and-watch approach, did not want to worry family/friends, denial, lack of trust in the doctor, difficult making an appointment, fear, embarrassment about symptoms and investigations	Thought the symptoms were serious, persistent symptoms, family history of cancer, insisted by partner or family member, opportunity to talk to GP in regular visit	Not specified
31	Pederson (2013)	Denmark	Cross-sectional	CRC	28 days (median)	136	Until seeking medical advice	Rectal bleeding (vs. no rectal bleeding)	Not specified	None
32	Estava (2013)	Spain	Cross-sectional	Colorectal	128 days	795	Until diagnosis	Family history of cancer	Perception of symptom seriousness (vomiting, abdominal pain, intestinal obstruction), trust in GP, symptom disclosure to family or friends	Female

**RB*: Rectal bleeding.

**CIBH*: Change in bowel habit.

Appendix 3.1: Help-seeking Behaviour Questionnaire used in the video vignette survey in Study 1

Section 1: Demographic Information

Section 1a

1. What is your age in years (as on last birthday)?
.....

2. In which country were you born?
 - a. Australia
 - b. Other (Please specify).....

3. How long have you been living in Australia for?
 - a. 5 years or less
 - b. 6–10 years
 - c. More than 10 years

4. Please indicate the highest level of formal education you have completed?
 - a. Less than year 10
 - b. Year 10
 - c. Year 12
 - d. Tertiary education (University or CAE)
 - e. Technical training (Trade/TAFE)
 - f. Other (Please specify).....

5. What is your current employment status?
 - a. Unemployed
 - b. Employed full-time
 - c. Employed part time
 - d. Student
 - e. Pensioner or on social security
 - f. Other (Please specify).....

6. What is your annual household income?
 - a. Less than \$40,000
 - b. \$41,000–\$80,000
 - c. \$81,000–\$120,000
 - d. \$120,000–\$160,000
 - e. More than \$1,60,000
 - f. I prefer not to answer this question

7. Which of the following best describes your marital status?
 - a. Married
 - b. De facto
 - c. Separated
 - d. Widowed
 - e. Divorced
 - f. Never Married

8. What is the post code of your place of residence?
9. Do you have a private health cover (e.g.: BUPA, HBF, Medibank, etc.)?
- a. Yes
 - b. No

Section 1b

10. How often do you see your GP?
- a. Never
 - b. Once a year or less
 - c. Several times a year
 - d. Once a month
 - e. 2–3 times a month
 - f. Once a week
 - g. Other (Please specify).....
11. Do you think seeing a GP takes too much time?
- a. Yes
 - b. No
 - c. Not sure
12. Do you think seeing a GP costs too much money?
- a. Yes
 - b. No
 - c. Not sure

Section 2: You are requested to watch the video and answer the following questions. Each video represents a different scenario and is independent of other videos. There are no right or wrong answers.

1. Do you think this man should seek advice from a health professional?

- a. Yes
- b. No
- c. Unsure

2. Which health professional should he seek advice from?

- a. GP
- b. Pharmacist/Chemist
- c. Nurse
- d. Others (Please specify).....
- e. Not sure

3. How soon should he seek advice?

- a. Today
- b. This week
- c. This month
- d. Not sure

4. We would like to know what you think about the following statements. You may agree or disagree based on your knowledge and understanding. There are no right or wrong answers.

		Strongly Disagree	Strongly Agree	Not sure	Agree	Strongly Agree
	Severity					
1	This man's symptoms may last a long time	1	2	3	4	5
2	These symptoms will interfere with his daily life	1	2	3	4	5
	Susceptibility					
3	It is likely that he will get worse if he ignores his symptoms	1	2	3	4	5
	Barriers					
4	Seeing a GP for these symptoms may be embarrassing	1	2	3	4	5
	Benefits					
5	If he sees his GP he is less likely to worry for these symptoms	1	2	3	4	5
6	Seeing a GP for these symptoms will reduce his chances of a bad outcome	1	2	3	4	5
	Confidence					
7	He can be confident that a GP can help with these symptoms	1	2	3	4	5

Appendix 3.2: Sample vignettes

1. I need some advice about my symptoms. I have been feeling a bit unwell for the past three **weeks**. I have noticed some **blood in my poo**. I have **lost around 2–3 kg weight** though my diet is still the same. I have also had **diarrhoea**. What do you reckon I should do about this?
2. I've had some symptoms and wanted your advice. I've been feeling unwell for the past three **days**. I have had **diarrhoea** and have noticed **blood in my poo**. I haven't lost any weight. What do you think I ought to do about this?
3. I need your advice about my health. I have been having **diarrhoea** for the past three **weeks**. I have not lost any weight or noticed blood in my poo.
4. I need your advice about my health. I've been feeling unwell for the past three **days**. I've noticed **blood in my poo**. I have not lost any weight and have not had diarrhoea.

Appendix 3.3: Responses to video vignettes

Age	Duration	Rectal bleeding	Diarrhoea	Weight loss	Expert	Referral (%)	GP (%)
Old	3 weeks	Yes	Yes	Yes	GP	85.1	77.7
Old	3 weeks	Yes	Yes	No	Other	88.1	63.6
Old	3 weeks	Yes	No	Yes	GP	76.9	68.6
Old	3 weeks	Yes	No	No	GP	60.3	51.7
Old	3 weeks	No	Yes	Yes	GP	85.7	53.8
Old	3 weeks	No	Yes	No	GP	77.9	41.8
Young	3 weeks	Yes	Yes	Yes	GP	90.0	84.2
Young	3 weeks	Yes	Yes	No	GP	81.7	61.7
Young	3 weeks	Yes	No	Yes	GP	71.2	64.4
Young	3 weeks	Yes	No	No	GP	55.0	49.2
Young	3 weeks	No	Yes	Yes	GP	82.0	52.3
Young	3 weeks	No	Yes	No	GP	83.2	47.9
Old	3 days	Yes	Yes	Yes	GP	78.3	53.0
Old	3 days	Yes	Yes	No	Other	79.5	52.1
Old	3 days	Yes	No	Yes	Other	58.8	54.6
Old	3 days	Yes	No	No	Other	52.2	46.0
Old	3 days	No	Yes	Yes	Other	59.8	26.8
Old	3 days	No	Yes	No	Other	64.3	21.7
Young	3 days	Yes	Yes	Yes	Other	81.7	57.4
Young	3 days	Yes	Yes	No	Other	73.7	47.4
Young	3 days	Yes	No	Yes	Other	47.9	44.4
Young	3 days	Yes	No	No	Other	41.0	40.2
Young	3 days	No	Yes	Yes	Other	61.8	30.9
Young	3 days	No	Yes	No	GP	40.8	10.7
Old	3 weeks	No	No	Yes	Other	27.6	25.9
Young	3 weeks	No	No	Yes	GP	29.7	26.3
Young	3 days	No	No	Yes	No	20.2	18.4
Old	3 days	No	No	Yes	No	23.5	21.0

Footnotes: The 'expert' column shows the consensus among 5 experts (No referral/refer to GP/refer to other health professional). The 'Referral' column shows the percentage of responses recommending referral to a health professional, while the 'GP' column shows the percentage of all responses recommending referral to a GP.

Appendix 4.1: Participant information sheet and consent form for Study 3 (Hospital)



Sir Charles Gairdner Hospital
PARTICIPANT INFORMATION SHEET

Lay Title: Beliefs and attitudes of men in regards consulting a doctor for bowel symptoms

Study Title: Help seeking behaviour of men in regards to lower bowel symptom

(Study 3)

Researchers: Dr. Devesh V Oberoi, Curtin University

Dr. Rupert Hodder, Department of General Surgery, SCGH

Prof. Moyez Jiwa, Curtin University

Please take time to read the following information carefully and to discuss it with your family, friends and general practitioner if you so wish. If any part of the information is not clear to you, or if you would like more information do not hesitate to ask us to explain it more fully. Make certain you do this before you sign the consent form to participate in this study.

Who is funding this study?

Curtin University

Contact persons:

If you have any questions about the study you can contact:

Devesh Oberoi: Phone No. (0425611233)

OR

Rupert Hodder: Phone No. (0437052377)

Decision to Participate:

Your decision to participate in this study is **voluntary**, that is, you may decide to be in this study or not take part in it at all. If do you decide to participate, you are able to change your mind at any time during the study. However, before you make any decision, it is important that you understand why this study is being done and what it will involve, including your rights and responsibilities. You will also be given a copy of this Participant Information Sheet and Consent Form to keep for your personal record.

Any decision you make will not affect your regular medical care or any benefit to which you would otherwise be entitled.

What is the purpose of this study?

The aim is to understand the attitudes, beliefs and experience men in regards to bowel symptoms and to draw inferences from their experience. The study will focus on men who have undergone colonoscopy and have been diagnosed with any benign bowel disease or functional bowel disorder.

Why is this study suitable to me?

You have been invited to participate in this study as you have undergone colonoscopy in the recent past.

How long will I be in this study?

You will be invited for a one-off interview which may last from 30–45 minutes and will be conducted in a closed room at Sir Charles Gardner Hospital.

What will happen if I decide to be in this study?

You will be informed about the project by your clinician. Should you agree to participate, the researcher (principal investigator) shall contact you for one-off interview to talk to you regarding your experience about these symptoms and about your decision to see a doctor and undergo colonoscopy. You will be interviewed by the researcher in a closed room at Sir Charles Gardner Hospital at the time that suits you the most. The interview will last from 30– 45 minutes. If you feel uncomfortable during the interview, you will be free to withdraw from the study without having to give any reasons. In this situation you will not be contacted by the researcher in future.

Are there any reasons I should not be in this study?

You should not be in this study if you are not able to converse, read or write in English.

What are the costs to me?

There will be no costs to you. You will be invited for a one-off interview at a time that is most convenient to you. Your parking ticket will be reimbursed.

What are the possible benefits of taking part, to me and to the wider community?

This study will help us to understand the experience of men who suffer from lower bowel symptoms and the factors that encourage them to see a doctor. It will also help us to determine if any steps could be taken to encourage men to seek medical advice at an earlier stage of their symptoms. An understanding of the men's help-seeking behaviour for these symptoms will help in developing public policy to encourage men to consult a Doctor for these symptoms sooner rather than later. Your involvement may benefit the society as a whole.

What are my alternatives if I do not want to participate in this study?

You do not have any obligation to participate in this study. Your decision to participate or not to participate in this study will not affect your current or future medical care.

What are the possible side effects, risks and discomforts of taking part?

No harm or costs are expected to come from your involvement in this study. You may choose not to answer any question that you may find personal or uncomfortable. If for any reason you choose to withdraw from the study you are free to do so without having to give any reason.

Will my taking part in this study be kept confidential?

The interview will be audiotaped and later will be transcribed into text. Any personal or health information obtained during the interviews will be kept private and highly confidential. Only the researchers of this study will have access to it. Your interview details will be given a unique number so that your identity will not be apparent to anyone else. All the participants' records will be kept in secured locker at Curtin Health Innovation Research Institute, Technology Park, Bentley. The information will be securely stored for a period of 5 years from the completion of the study and will be destroyed thereafter. The audio files will be stored in hard disk drive and will be destroyed after 5 years from the completion of the study. The result of the research will be made available to other health professionals through medical journals or meetings, but the participants will not be identifiable at any stage of the project or thereafter. Authorised representatives of the sponsor, the study doctor, the Hospital's Human Research Ethics Committee, Research Governance and specific pharmaceutical regulatory bodies may require access to your study records to audit study

procedures and/or data. As well, some of your information may be sent to research staff in other countries for similar reasons. If this should occur, these personnel are required to comply with the privacy laws that protect you when dealing with your information. By taking part in this study you are agreeing not to restrict the use of any data even if you withdraw. However, your rights under any applicable data protection laws are not affected.

How can I find out the results of this study?

The results of the study will also be published in peer-reviewed journals and presented at national and international conferences. You may find out about the study results by reading these articles or by contacting the hospital or researcher directly.

Who has reviewed this study?

The Sir Charles Gairdner Group Human Research Ethics Committee has reviewed this study and has given its approval for the conduct of this research study. In doing so, this research conforms to the principles set out by the National Statement on Ethical Conduct in Human Research and abides by the Good Clinical Practice Guidelines. The study has also been reviewed and approved by the Curtin University Human Research Ethics Committee.



CONSENT FORM

Lay Title: Beliefs and attitudes of men in regards consulting a doctor for bowel symptoms

Study title: Help seeking behaviour of men in regards to lower bowel symptoms

(Phase 1)

Researchers: Devesh V Oberoi, Rupert Hodder, Moyez Jiwa>>

Participant Name: _____

Date of Birth: _____

NOTE: If you are still unclear about anything you have read in the Participant Information Sheet and Consent Form, please speak to your doctor before signing this Consent.

1. I have been given information, both verbally and in writing, about this study and having had time to consider it I am now able to make an informed decision to participate.
2. I have been told about the potential benefits and known risks of taking part in this study and I understand what this means to me.
3. I have been given the opportunity to have a member of my family or a friend with me when this study was being explained to me. I have been able to ask questions and have had all my questions answered.
4. I know that I do not have to take part in this study, and that my decision to take part is voluntary. I understand that I can withdraw from this study at any time without this decision affecting my medical care.
5. I understand that participating in this study does not affect any right to compensation, which I may have under statute or common law.

6. I accept that by taking part in this research, that any information obtained about me during the study may be published, provided that my name **and** other identifying information **are** not used.

Name of Participant	Signature of Participant	Date
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Name of Researcher	Signature of Researcher	Date
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The Sir Charles Gairdner Group Human Research Ethics Committee has granted approval for the conduct of this study. If you have any concerns about the ethics or code of practice of the study, please contact the Executive Officer of the Sir Charles Gairdner Group Human Research Ethics Committee on (08) 9346 2999.

Study participants are to receive a copy of the Participant Information Sheet and Consent Form for their personal record.

Appendix 4.2: Participant information sheet and consent form for Study 4 (Hospital)



Sir Charles Gairdner Hospital
PARTICIPANT INFORMATION SHEET

Lay Title: Beliefs and attitudes of men in regards consulting a doctor for bowel symptoms

Study Title: Help seeking behaviour of men in regards to lower bowel symptoms (Study 4)

Researchers: Dr. Devesh V Oberoi, Curtin University

Dr. Rupert Hodder, Department of General Surgery, SCGH

Prof. Moyez Jiwa, Curtin University

Please take time to read the following information carefully and to discuss it with your family, friends and general practitioner if you so wish. If any part of the information is not clear to you, or if you would like more information do not hesitate to ask us to explain it more fully. Make certain you do this before you sign the consent form to participate in this study.

Who is funding this study?

Curtin University

Contact persons:

If you have any questions about the study you can contact:

Devesh Oberoi: Phone No. (0425611233)

OR

Rupert Hodder: Phone No. (0437052377)

Decision to Participate:

Your decision to participate in this study is **voluntary**, that is, you may decide to be in this study or not take part in it at all. If do you decide to participate, you are able to change your mind at any time during the study. However, before you make any decision, it is important that you understand why this study is being done and what it will involve, including your rights and responsibilities. You will also be given a copy of this Participant Information Sheet and Consent Form to keep for your personal record.

Any decision you make **will not** affect your regular medical care or any benefit to which you would otherwise be entitled.

What is the purpose of this study?

The aim is to understand the attitudes, beliefs and experience of men seeking medical advice for lower bowel symptoms and to draw inferences from the experience. The study will focus on men who have undergone colonoscopy and have been diagnosed with malignant bowel disease or colorectal cancer.

Why is this study suitable to me?

You have been invited to participate in this study as you have undergone colonoscopy in the recent past and have been diagnosed with bowel disease.

How long will I be in this study?

You will be invited for an interview which may last from 30–45 minutes and will be conducted in a closed room at Sir Charles Gardner Hospital. Should need be, the researcher may call you for a follow-up interview which can be done over phone or in person as per your choice.

What will happen if I decide to be in this study?

You will be informed about the project by your clinician. Should you agree to participate, the researcher (principal investigator) shall contact you for an interview to talk to you regarding your experience about these symptoms and about your decision to see a doctor and undergo colonoscopy. You will be interviewed by the researcher in a closed room at Sir Charles Gardner Hospital at the time that suits you the most. The interview will last from 30–45 minutes. If you feel uncomfortable during the interview, you will be free to withdraw from the study without having to give any reasons. In this situation you will not be contacted by the researcher in future.

Are there any reasons I should not be in this study?

You should not be in this study if you are not able to converse, read or write in English.

What are the costs to me?

There will be no costs to you. You will be invited for an interview at the time that is most convenient to you. Your parking ticket will be reimbursed.

What are the possible benefits of taking part, to me and to the wider community?

This study will help us to understand the experience of men who suffer from lower bowel symptoms and the factors that lead them to see a doctor. It will also help us to determine if any steps could be taken to facilitate men to seek medical advice at an earlier stage of their symptoms. Your involvement may benefit the society as a whole.

What are my alternatives if I do not want to participate in this study?

You do not have any obligation to participate in this study. Your decision to participate or not to participate in this study will not affect your current or future medical care.

What are the possible side effects, risks and discomforts of taking part?

No harm or costs are expected to come from your involvement in this study. You may choose not to answer any question that you may find personal or uncomfortable. If for any reason you choose to withdraw from the study you are free to do so without having to give any reason.

Will my taking part in this study be kept confidential?

The interview will be audiotaped and later will be transcribed into text. Any personal or health information obtained during the interviews will be kept private and highly confidential. Only the researchers of this study will have access to it. Your interview details will be given a unique number so that your identity will not be apparent to anyone else. All the participants' records will be kept in secured locker at Curtin Health Innovation Research Institute, Curtin University Technology Park, Bentley. The information (both the audio and the text files) will be securely stored for a period of 5 years from the completion of the study and will be destroyed thereafter. The audio files will be stored in hard disk drive and will be destroyed after 5 years from the completion of the study. The result of the research will be made available to other health professionals through medical journals or meetings, but the participants will not be identifiable at any stage of the project or thereafter. Authorised representatives of the sponsor, the study doctor, the Hospital's Human Research Ethics Committee, Research Governance and specific pharmaceutical regulatory bodies may

require access to your study records to audit study procedures and/or data. As well, some of your information may be sent to research staff in other countries for similar reasons. If this should occur, these personnel are required to comply with the privacy laws that protect you when dealing with your information. By taking part in this study you are agreeing not to restrict the use of any data even if you withdraw. However, your rights under any applicable data protection laws are not affected.

How can I find out the results of this study?

The results of the study will also be published in peer-reviewed journals and presented at national and international conferences. You may find out about the study results by reading these articles or by contacting the hospital or researcher directly.

Who has reviewed this study?

The Sir Charles Gairdner Group Human Research Ethics Committee has reviewed this study and has given its approval for the conduct of this research study. In doing so, this research conforms to the principles set out by the National Statement on Ethical Conduct in Human Research and abides by the Good Clinical Practice Guidelines. The study has also been reviewed and approved by the Curtin University Human Research Ethics Committee.



CONSENT FORM

Lay Title: Beliefs and attitudes of men in regards consulting a doctor for bowel symptoms

Study Title: Help seeking behaviour of men in regards to lower bowel symptoms

(Phase 2)

Researchers: Devesh V Oberoi, Rupert Hodder, Moyez Jiwa

Participant Name: _____

Date of Birth: _____

NOTE: If you are still unclear about anything you have read in the Participant Information Sheet and Consent Form, please speak to your doctor before signing this Consent.

1. I have been given information, both verbally and in writing, about this study and having had time to consider it, I am now able to make an informed decision to participate.
2. I have been told about the potential benefits and known risks of taking part in this study and I understand what this means to me.
3. I have been given the opportunity to have a member of my family or a friend with me when this study was being explained to me. I have been able to ask questions and have had all my questions answered.
4. I know that I do not have to take part in this study, and that my decision to take part is voluntary. I understand that I can withdraw from this study at any time without this decision affecting my medical care.
5. I understand that participating in this study does not affect any right to compensation, which I may have under statute or common law.

6. I accept that by taking part in this research, that any information obtained about me during the study may be published, provided that my name **and** other identifying information **are** not used.

Name of Participant	Signature of Participant	Date
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Name of Researcher	Signature of Researcher	Date
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The Sir Charles Gairdner Group Human Research Ethics Committee has granted approval for the conduct of this study. If you have any concerns about the ethics or code of practice of the study, please contact the Executive Officer of the Sir Charles Gairdner Group Human Research Ethics Committee on (08) 9346 2999.

Study participants are to receive a copy of the Participant Information Sheet and Consent Form for their personal record.

Appendix 4.3: Participant information sheet for Study 1



CURTIN UNIVERSITY

Division of Health Sciences/Curtin Health Innovation Research Institute (CHIRI)

PARTICIPANT INFORMATION SHEET

Help seeking behaviour of men in regards to lower bowel symptoms (Study 1)

Investigator: Dr. Devesh V Oberoi

Please take time to read the following information carefully and discuss it with your friends, family and general practitioner (GP) if you wish. Ask us any question if some part of the information is not clear to you or if you would like more information. Please do this before you sign the consent form.

Who is funding this study?

Curtin University

Contact person:

Should you have questions about the study, you may contact the researcher on Phone No. 61-0425611233 or send an e-mail to d.oberoi@student.curtin.edu.au

All the study participants will be provided with a copy of the Information Sheet and Consent Form for their personal records. You may decide to be in the study or not take part at all. If you do decide to take part in this study, you may stop at any time. However, before you decide, it is important that you know why this research is being done and what it will involve. No matter what you decide, this decision will not lead to any penalty or affect your regular medical care or any benefit to which you are otherwise entitled.

This Information Sheet will explain the study and will include details such as:

- x Why this study might be suitable for you
- x The nature of your involvement
- x Your rights and responsibilities

What is the purpose of the study?

The study aims to understand and explore the help-seeking behaviour of men in regards to their lower bowel symptoms like persistent diarrhoea or constipation, abdominal pain and bleeding from rectum i.e., blood on toilet paper or in toilet bowl.

Why is this study suitable to me?

Only men can participate in this study. Participants need to be considered as adult (+18) at the time of recruitment. Anyone, regardless of whether or not they have these symptoms can participate. One needs to have internet connection to be able to participate in this study.

What will happen if I decide to be in this study?

You will be contacted by the researcher and will be provided needed information to participate in the study. You will be required to watch eight short video clips (20–30 seconds each) administered to your Email ID via internet and answer a short questionnaire subsequent to each video. At the end of the study you will be requested to send back your responses to the researcher via Email. Researcher may contact you during study period for support or asking specific questions or checking something with you.

Will I be required to fill any documents?

Yes; you will be required to answer a short questionnaire subsequent to watching each video. Each questionnaire will take around 5 minutes.

Are there any reasons I should not be in this study?

You should not be in this study if you are not able to converse or write in English or communicate via Email.

What are the costs to me?

There will be no costs to you.

Will I be paid during this study?

You will be awarded a notional amount in the form of shopping voucher for being involved in this study.

What are the possible benefits of taking part?

This study will enable us to determine what men think of and how do they go about seeking help for lower bowel symptoms and their motivation to consult a doctor for these symptoms. The prevalence of these symptoms is high and their progression to bowel cancer is modest. An understanding of the men's help-seeking behaviour for these symptoms will help in developing public policy to encourage men to consult a Doctor for these symptoms sooner rather than later. Your involvement may benefit the society as a whole.

What are the possible side effects, risks and discomforts of taking part?

No harm or costs are expected to come from your involvement in this study. The survey questionnaire may contain questions that may be personal or private. If for any reason you find these upsetting you may choose not to answer. If for any reason you choose to withdraw from the study you are free to do so without having to give a reason.

Will my participation in this study be kept confidential?

The researchers will need to collect personal data about you, which may be sensitive. Examples of such data include your name, contact details, date of birth and relevant health information.

However, any personal or health information will be kept private and confidential. It will be stored securely and only authorised persons, who understand it must be kept confidential, will have access to it. Your study details will be given a number so that your identity will not be apparent. The data collected will be stored securely in the Curtin Health Innovation Research Institute, Technology Park during the study and in a locked archive for six years from the time the study is closed, and may be destroyed at any time thereafter.

The result of the research will be made available to other health professionals through medical journals or meetings, but you will not be identifiable.

Will I find out the results of the study?

In due course, the researchers will send you information about the results of the study. The results of the study will also be published in peer-reviewed journals and presented at national and international conferences. You may find out about the study results by reading these articles or by contacting the researcher directly.

Appendix 4.4: Participant information sheet for Study 2



CURTIN UNIVERSITY

Division of Health Sciences/Curtin Health Innovation Research Institute (CHIRI)

PARTICIPANT INFORMATION SHEET

Help seeking behaviour of men in regards to lower bowel symptoms (Study 2)

Investigator: Dr. Devesh V Oberoi

Please take time to read the following information carefully and discuss it with your friends, family and general practitioner (GP) if you wish. Ask us any question if some part of the information is not clear to you or if you would like more information. Please do this before you sign the consent form.

Who is funding this study?

Curtin University

Contact person:

Should you have questions about the study you may contact the researcher on Phone No. 61-0425611233 or send an e-mail to d.oberoi@student.curtin.edu.au.

All study participants will be provided with a copy of the Information Sheet and Consent Form for their personal records. You may decide to be in the study or not take part at all. If you do decide to take part in this study, you may stop at any time. However, before you decide, it is important that you know why this research is being done and what it will involve. No matter what you decide, this decision will not lead to any penalty or affect your regular medical care or any benefit to which you are otherwise entitled.

This Information Sheet will explain the study and will include details such as:

- x Why this study might be suitable for you
- x The nature of your involvement
- x Your rights and responsibilities

What is the purpose of the study?

This project aims to explore and understand the help-seeking behaviour of men who have lower bowel symptoms (like persistent diarrhoea or constipation, abdominal pain and rectal bleeding i.e., blood on toilet paper or in the toilet bowl) and have not consulted the doctor.

Why is this study suitable to me?

Patients are eligible if they have lower bowel symptoms like rectal bleeding, diarrhoea or constipation persisting for >4–6 weeks, and/or persistent abdominal pain and/or rectal bleeding and visit a pharmacy for advice/medication for any or all of these symptoms. Participants need to be considered as adult men (+18) at the time of recruitment.

What will happen if I decide to be in this study?

Should you wish to participate, you will be contacted by the researcher and will be provided by needed information if required by you. You will be required to undergo a semi-structured interview about your experience of suffering from these symptoms and your motivation to seek help for the symptoms from the pharmacist. Interview will be conducted at your choice of venue: University campus, your home or at the pharmacy. The interview will be tape recorded for transcription and data analysis.

Will I be required to fill any documents?

You will be required to sign a consent form demonstrating your willingness to participate in the study.

Are there any reasons I should not be in this study?

You should not be in this study if you are not able to converse, read or write in English.

What are the costs to me?

There will be no costs to you.

Will I be paid during this study?

You will be paid a notional amount such a shopping voucher for being involved in this study.

What are the possible benefits of taking part?

This study will enable us to determine why people with lower bowel symptoms prefer to consult the pharmacist or buy the OTC available medicines rather than consulting a doctor/GP. There is evidence that these symptoms may gradually progress to bowel cancer. Your involvement may benefit the society as a whole as it will help us in determining ways to encourage people with these symptoms to consult a doctor sooner rather than later. An understanding of the men's help-seeking behaviour for these symptoms will help in developing public policy to encourage men to consult a Doctor for these symptoms sooner rather than later.

What are the possible side effects, risks and discomforts of taking part?

No harm or costs are expected to come from your involvement in this study. The surveys may contain questions that are personal or private. If for any reason you find these upsetting you may choose not to answer. If for any reason you choose to withdraw from the study you are free to do so without having to give a reason.

Will my participation in this study be kept confidential?

The researchers will need to collect personal data about you, which may be sensitive. Examples of such data include your name, contact details, date of birth and relevant health information.

However, any personal or health information will be kept private and confidential. It will be stored securely and only authorised persons, who understand it must be kept confidential, will have access to it. Your study details will be given a number so that your identity will not be apparent. The data collected will be stored securely in the Curtin Health Innovation Research Institute, Technology Park during the study and in a locked archive for six years from the time the study is closed, and may be destroyed at any time thereafter.

The result of the research will be made available to other health professionals through medical journals or meetings, but you will not be identifiable.

Will I find out the results of the study?

In due course, the researchers will send you information about the results of the study. The results of the study will also be published in peer-reviewed journals and presented at national and international conferences. You may find out about the study results by reading these articles or by contacting the researcher directly.

Appendix 4.5: Participant information sheet for Study 3



CURTIN UNIVERSITY

Division of Health Sciences/Curtin Health Innovation Research Institute (CHIRI)

PARTICIPANT INFORMATION SHEET

Help seeking behaviour of men in regards to lower bowel symptoms (Study 3)

Investigator: Dr. Devesh V Oberoi

Please take time to read the following information carefully and discuss it with your friends, family and general practitioner (GP) if you wish. Ask us any question if some part of the information is not clear to you or if you would like more information. Please do this before you sign the consent form.

Who is funding this study?

Curtin University

Contact person:

Should you have questions about the study you may contact researchers on Phone No. 61-0425611233 or send an e-mail to d.oberoi@student.curtin.edu.au or the supervisor through Email M.Jiwa@curtin.edu.au

All study participants will be provided with a copy of the Information Sheet and Consent Form for their personal records. You may decide to be in the study or not take part at all. If you do decide to take part in this study, you may stop at any time. However, before you decide, it is important that you know why this research is being done and what it will involve. No matter what you decide, this decision will not lead to any penalty or affect your regular medical care or any benefit to which you are otherwise entitled.

This Information Sheet will explain the study and will include details such as:

- x Why this study might be suitable for you
- x The nature of your involvement
- x Your rights and responsibilities

What is the purpose of the study?

The aim is to understand the help-seeking behaviour and the experience of men diagnosed with benign and chronic colorectal diseases to draw inferences from the experience.

Why is this study suitable to me?

Patients are eligible if they are undergoing colonoscopy.

Do I have to fill in any documents?

Yes, you will have to sign a consent form before you can participate in the study.

What will happen if I decide to be in this study?

You will be alerted about the project by your clinician and it will be up to you to decide if you wish to participate. Once you agree to participate, the researcher shall contact you for an interview to explore your experience about these symptoms and about your decision to seek medical help and undergo colonoscopy.

Are there any reasons I should not be in this study?

You should not be in this study if you are not available you are not able to converse, read or write in English.

What are the costs to me?

There will be no costs to you.

Will I be paid during this study?

You will be paid a notional amount in the form of shopping voucher_for being involved in this study.

What are the possible benefits of taking part?

This study will enable us to understand the experience of men who suffer from lower bowel symptoms and the factors that encourage them to consult a doctor and also to determine if steps could be taken to encourage men to seek medical advice at an earlier stage of their symptoms. An understanding of the men's help-seeking behaviour for these symptoms will help in developing public policy to encourage men to consult a Doctor for these symptoms sooner rather than later. Your involvement may benefit the society as a whole.

What are the possible side effects, risks and discomforts of taking part?

No harm or costs are expected to come from your involvement in this study. The interview may contain questions that are personal or private. If for any reason you find these upsetting you may choose not to answer. If for any reason you choose to withdraw from the study you are free to do so without having to give a reason.

Will my participation in this study be kept confidential?

The researchers will need to collect personal data about you, which may be sensitive. Examples of such data include your name, contact details, date of birth and relevant health information.

However, any personal or health information will be kept private and confidential. It will be stored securely and only authorised persons, who understand it must be kept confidential, will have access to it. Your study details will be given a number so that your identity will not be apparent. The data collected will be stored securely in the Curtin Health Innovation Research Institute during the study and in a locked archive for six years from the time the study is closed, and may be destroyed at any time thereafter.

The result of the research will be made available to other health professionals through medical journals or meetings, but you will not be identifiable.

Will I find out the results of the study?

In due course, the researchers will send you information about the results of the study. The results of the study will also be published in peer-reviewed journals and presented at national and international conferences. You may find out about the study results by reading these articles or by contacting the hospital or researcher directly.

Appendix 4.6: Participant information sheet for Study 4



CURTIN UNIVERSITY
Division of Health Sciences/Curtin Health Innovation Research Institute (CHIRI)

PATIENT INFORMATION SHEET

Help seeking behaviour of men in regards to lower bowel symptoms (Study 4)

Investigator: Dr. Devesh V Oberoi

Please take time to read the following information carefully and discuss it with your friends, family and general practitioner (GP) if you wish. Ask us any question if some part of the information is not clear to you or if you would like more information. Please do this before you sign the consent form.

Who is funding this study?

Curtin University

Contact person:

Should you have questions about the study you may contact the researcher on Phone No. 61-0425611233 or send an e-mail to d.oberoi@curtin.edu.au

All study participants will be provided with a copy of the Information Sheet and Consent Form for their personal records. You may decide to be in the study or not take part at all. If you do decide to take part in this study, you may stop at any time. However, before you decide, it is important that you know why this research is being done and what it will involve. No matter what you decide, this decision will not lead to any penalty or affect your regular medical care or any benefit to which you are otherwise entitled.

This Information Sheet will explain the study and will include details such as:

- x Why this study might be suitable for you
- x The nature of your involvement
- x Your rights and responsibilities

What is the purpose of the study?

The aim is to understand the help-seeking behaviour and the experience men who have been diagnosed with bowel pathology or colorectal cancer.

What will happen if I decide to be in this study?

You will be alerted about the project by your clinician and it will be up to you to decide if you wish to participate. Once you agree to participate, the researcher shall contact you for an interview to explore your experience about these symptoms and about your decision to seek medical help and undergo colonoscopy.

Researcher may contact you during study period for support or asking specific questions or checking something with you.

Are there any reasons I should not be in this study?

You should not be in this study if you are not able to converse or write in English.

What are the costs to me?

There will be no costs to you.

Will I be paid during this study?

You will be paid a notional amount such as shopping voucher for being involved in this study.

What are the possible benefits of taking part?

This study will enable us to understand the experience of men who suffer from lower bowel symptoms and the factors that encourage them to consult a doctor and also to determine if steps could be taken to encourage men to seek medical advice at an earlier stage of their symptoms.

What are the possible side effects, risks and discomforts of taking part?

No harm or costs are expected to come from your involvement in this study. The interview may contain questions that are personal or private. If for any reason you find these upsetting you may choose not to answer. If for any reason you choose to withdraw from the study you are free to do so without having to give a reason.

Will my participation in this study be kept confidential?

The researchers will need to collect personal data about you, which may be sensitive. Examples of such data include your name, contact details, date of birth and relevant health information.

However, any personal or health information will be kept private and confidential. It will be stored securely and only authorised persons, who understand it must be kept confidential, will have access to it. Your study details will be given a number so that your identity will not be apparent. The data collected will be stored securely in the Curtin Health Innovation Research Institute during the study and in a locked archive for six years from the time the study is closed, and may be destroyed at any time thereafter.

The result of the research will be made available to other health professionals through medical journals or meetings, but you will not be identifiable.

Will I find out the results of the study?


In due course, the researchers will send you information about the results of the study. The results of the study will also be published in peer-reviewed journals and presented at national and international conferences. You may find out about the study results by reading these articles or by contacting the hospital or researcher directly.

Appendix 4.7: Copyright Permissions

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Nov 30, 2015

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